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Marcia H. Rioux
Alexis Buettgen
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José Viera
Editors

Handbook of Disability

Critical Thought and Social Change in a Globalizing World

Springer

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Ezra Zubrow • José Viera
Editors

Handbook of Disability

Critical Thought and Social Change in a Globalizing World

With 152 Figures and 33 Tables

Springer

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This book is dedicated to the people who were pivotal in the disability movement and the organizations of persons with disabilities who changed how things were, what they are now, and where they will need to be. This book is also dedicated to all those who will continue to fight for human rights and social justice in the spirit of Marcia Rioux and Bengt Lindqvist.

Acknowledgments

First and most importantly, we want to thank Marcia Rioux whose idea this book was. In addition, she impacted every one of the co-editors, section editors, and contributors in many ways.

For some she was a partner; for others a teacher; for others a colleague; for others a role model; for others a visionary; for others an icon; for others an advocate; for others a friend. We want to thank our families for their patience and their belief in this project when we asked them to forego all the small and major family activities because we were writing and editing this book. Thank you Trevor and Seth Russell, Zoe Zucar, Liz Bucar, Alexis and Marcia Zubrow, Alanya, Carlos, Reuben and Lily Zuniga, Rosana Alancay and Helena Viera.

We also want to thank our dedicated section editors for their commitment to this Handbook. We thank you for your ongoing support, writing and curating the sections of this book. You not only helped find the numerous contributors, but your perceptions and editing skills made each chapter and section better. Furthermore, you were indomitable in collecting manuscripts and helping us focus on the central issues.

This Handbook is the result of the brilliant and diverse contributions of all the authors of the 92 chapters included herein. We thank you for sharing your critical thoughts, insights, and experiences with us and our readers. We deeply appreciate your openness and vulnerability in participating in this project, as well as your creative expressions. Many of you come from diverse cultural and national backgrounds. We thank you for your willingness to adapt to a single format and style.

The Handbook would not have been possible without the tremendous support of our publisher – Springer, in particular the efforts and responsiveness of Shobana Lenin and Juby George. We particularly wish to thank you for picking up the threads and reviving the project after a 2-year delay because of Marcia's death. We thank you for making the Meteor system accessible to our authors (even though the co-editors in chief were initially doubtful of the necessity for the Meteor system and agreed to do so only because you wanted us to). We soon came to realize that it actually is a wonderful tool and we could not have accomplished as much as we did in a relatively short time without it. You were always there to assist us with technical, administrative, and other important details needed to ensure the book was developed and completed.

There were numerous institutions that have been instrumental and supportive of this work: York University, where Marcia Rioux was a distinguished professor, and the School of Health Policy and Management as well as the Critical Disabilities Studies Program. We want to acknowledge and thank Marina Morrow – Professor and Chair of the School of Health Policy and Management at York – for her continuous support to DRPI and the programs that Marcia created over many years, not the least of which was this book. The University at Buffalo and its Anthropology Department provided office and laboratory support, and many contributors had institutional support from IDA. McMaster University and the Institute for Work and Health have provided financial support for Alexis' postdoctoral fellowship – of which the book is a part. Thank you to Emile Tompa for your ongoing postdoctoral guidance and mentorship throughout this project.

Next to Sukaina Dada and Tammy Bernasky, you were truly integral to the development of the Handbook alongside Marcia. The creation, design, structure, and development of the Handbook was indeed a result of your commitment and dedication to this project – especially in the midst of great challenges. Thank you for working closely with Springer to ensure the Meteor system was accessible to all our editors and authors. Thank you for your drafts and creative versions of the text to make it accessible to all. Thank you for your communication and amazing organizational skills.

We want to acknowledge that this Handbook was created because of our capacity to communicate online. Not only could we communicate all over the world easily and with the ability to see and share material, but we could connect virtually and accessibly with our editors and contributors. We are grateful for our digital access in Canada and recognize that this is not as freely and easily available throughout the world. We hope that the future will bring digital equity and accessibility to all people of the world. We acknowledge Zoom, Teams, Skype, and WhatsApp for making our worldwide communication better.

Finally, this book would not have been possible without the intellectual and advocacy visions of Bengt Lindqvist who together with Marcia Rioux changed the paradigm.

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About the Editors

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Marcia H. Rioux was a Distinguished Research Professor and Professor Emerita in the School of Health Policy and Management at York University's Faculty of Health. Nationally and internationally, Professor Rioux was regarded as a leading legal scholar and pioneer in the field of human rights and equity. She held a PhD in jurisprudence and social policy from the University of California, Berkeley. In addition to being named a Distinguished Research Professor by York University, Professor Rioux was the Director at York University's Institute for Health Research. She was the Co-Founder and first Chair of the School of Health Policy and Management as well as the Critical Disabilities Studies program. She was a driving force in the promotion of disability rights and the enhancement of opportunities for marginalized people. She played a leadership role in the United Nations Convention on the Rights of Persons with Disabilities and published widely in the area of disability and human rights. She was a Co-Founder of Disability Rights Promotion International, which now monitors rights for people with disabilities in more than 62 countries. She was a Fellow of the Institutes of Advanced Studies in the UK and Australia. Professor Rioux was the recipient of the Lieutenant Governor's Community Volunteer Award in recognition of her contributions to Ontario communities. In 2014, she was invested into the Order of Canada for her scholarship in the field of social justice and for her advancement of the rights of persons with disabilities. Professor Rioux lectured throughout the Americas, Europe, Africa, and Asia. She was a visiting scholar and Professor at a number of international institutions, including the University of Zagreb in Croatia and LaTrobe University in Australia. She edited a number of collected volumes and more than 70 book chapters and articles on human rights. Marcia died in September 2021. Her most recent project was this Handbook.

Alexis Buettgen
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Alexis Buettgen is a community-engaged scholar with an interdisciplinary academic background in community psychology and critical disability studies. Dr. Buettgen has over 15 years of experience in community-based participatory research and evaluation as a Senior Researcher at several community-based research organizations and organizations of people with disabilities (OPDs). Prior to this, Dr. Buettgen worked in a variety of community settings providing direct support to individuals with various experiences of oppression and marginalization, including people with various disabilities. These community experiences have informed her research program to critically examine issues of poverty, exclusion, and intersectional approaches to promote equity, and social and environmental justice. Dr. Buettgen holds academic appointments in the Department of Economics and School of Rehabilitation Science at McMaster University, and the Critical Disability Studies program at York University. Her scholarship aims to bridge the gap between academic knowledge and community action using a critical theoretical, human rights, and disability justice approach. She is dedicated to participatory and collaborative research examining the influence of economic and political environments on the progressive realization of disability inclusion. Her work connects the local with the global through fieldwork carried out at local, national, regional, and international levels. Her record of publications includes journal articles, invited book chapters, a monograph, and numerous reports commissioned by international, national, and local government agencies, OPDs, other disability organizations, and NGOs. Her scholarly publications have appeared in leading international peer-reviewed journals in the fields of disability studies, health sciences, human rights, and the social economy. Dr. Buettgen has been an invited speaker, guest lecturer, and course instructor on the topics of critical theory, human rights, global health, climate justice, intersectionality, and applied research for social justice at numerous universities and community organizations.

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Ezra Zubrow was educated at Harvard and the University of Arizona. He is an Anthropologist presently holding positions at the Universities of Cambridge, Buffalo, and Toronto as well as previously teaching at Stanford. He has been a fellow at various Institutes for Advanced Research in Europe and Australia. He has a broad range of interests focusing on the demographic, ecological, and spatial aspects of social and physical environments as well as disability. He has written or edited 10+ books, 150+ articles as well as received 20+ million dollars of grants. Among his writings are two co-written books – *The Atlas of Literacy and Disability* and *The Landscape of Literacy and Disability.*

Over the last two decades, he has been the Vice President and President of a labor union as well as the chair of a faculty senate. During these tenures, he actively made changes to promote human rights and he has served on various International Commissions on Law and Environment. An internationalist, he has done over 50 fieldwork expeditions in North America, South America, the Middle East, Europe, and Asia. Most recently, he is focusing on the circumpolar region.

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José Viera has more than 18 years of experience working nationally and internationally in the field of human rights and inclusive development. As a person with a disability, Mr. Viera has a personal commitment to improving the lives of persons with disabilities and advocating for their human rights. Mr. Viera is the Advocacy Director of the International Disability Alliance and was the Chief Executive Officer for the World Blind Union (WBU), a global organization with a broad international membership of over 300 organizations at the sub-national and regional levels in over 196 countries. Mr. Viera is also the Global Disability Summit Secretariat Senior Manager. The Global Disability Summit is a world-leading and pioneering event that unites the global effort for momentum toward the inclusion of the world's poorest and most neglected people. In addition, Mr. Viera is the Permanent Representative of the UN Stakeholder Group of Persons with Disabilities for Sustainable Development, also an Independent Board Member of CBM Global Disability Inclusion, as well as the former President of the Federation of the Blind of Argentina. Before joining WBU, Mr. Viera was Director of the Latin American Regional Center for Disability Rights Promotion International, which is a global monitoring rights system where he led regional and global initiatives to promote the ratification and implementation of the UN CRPD and the Agenda 2030. In addition, Mr. Viera has more than 10 years of experience as Associate Professor at the International Studies Department of Siglo 21 University in Argentina, lecturing on issues related to sustainable development and international cooperation. Mr. Viera holds a bachelor's degree in International Studies and a master's degree in Management of Development. Mr. Viera has contributed to various publications and research projects on disability and development with a special focus on the Global South.

About the Associate Editors

Tammy Bernasky has a PhD in Critical Disability Studies from York University. Using an intersectional approach, her research is focused on understanding the impacts of oppression and developing pathways to empowerment. Centering story-telling in her research, Tammy specializes in addressing gender-based violence in the disability community.

Dr. Sukaina Dada has been working in the areas of children's health, social justice, and disability rights for over 15 years. She is a critical pediatric occupational therapist and the Founder and Executive Director of SMILE Canada – Support Services, a Canadian non-profit organization that supports racialized disabled children and youth and their families. Dr. Sukaina holds a PhD in Critical Disability Studies from the School of Health Policy and Management at York University. Her research is focused on the critical intersections of displacement and disablement, examining why disabled refugees are continuously left out of critical conversations on human rights, disability justice, and the social determinants of health and disability.

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Francisco J. Bariffi, an academic, lawyer, and advocate, is deeply dedicated to human rights and disability rights. Presently a Postdoctoral Researcher at University Carlos III of Madrid (UC3M), he boasts a PhD in International Human Rights from the same institution. His vast expertise includes teaching postgraduate courses in countries like South Africa, Italy, Spain, and Brazil, among others. Widely respected for his lectures and talks worldwide, he served as a legal attorney from 2008 to 2014, specializing in civil, administrative, and family law. Between 2014 and 2021, he was a judge's assistant at the National Appeal Chamber of Mar del Plata, Argentina, focusing on human rights and criminal law.

Internationally, Francisco advised the Spanish Government during the UN-CPRD negotiations in 2005–2006 and contributed to various UN and regional human rights bodies. He has collaborated with EU agencies and served on advisory boards in Spain and Argentina, influencing law reforms in several countries. Beyond academia, Bariffi actively engages in community outreach, legal consultancy, and reporting. Fluent in English, Spanish, and Italian, his advocacy for human rights remains unparalleled.

Serida L. Catalano
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Dr. Serida L. Catalano is a renowned scholar in public policy, accessibility, and neurodiversity, with over a decade of managerial and research experience in non-profit and academic sectors. Her research has significantly contributed to social cohesion policies, especially concerning gender equality and inclusivity for marginalized demographics. Dr. Catalano has assisted government agencies in the UAE with implementing innovative educational methods and offered vital consultancy for aligning national laws with the UN Convention for the Rights of People with Disabilities (CRPD). Currently, as World Enabled's Program Director, she collaborates with cities and governments worldwide to promote inclusive urban development. Additionally, she is a Resident Research Fellow at the University of Berkeley, focusing on inclusive policies for neurodivergence.

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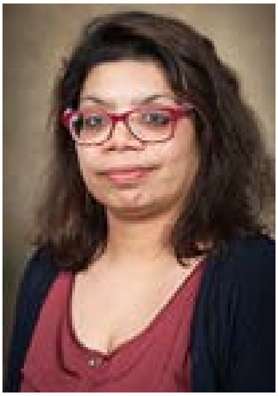
Mary Crock has worked in the area of immigration and refugee law since 1985. She is a Professor of Public Law at the University of Sydney's Law School. An Accredited Specialist in Immigration Law since 1994, she has served on a variety of national, state, and NGO bodies relating to immigration, refugees, disability, and child protection. Professor Crock has written extensively on issues related to immigration and refugee law, authoring 14 books, and over 80 book chapters, refereed articles, and reports. She has had a research focus on the laws, policies, and practices involving persons with disabilities in forced migration since 2010, building on a long-standing interest in children and other vulnerable migrants. Together with her husband Professor Emeritus Ron McCallum AO, her work with refugees with disabilities was recognized in December 2015 with the award of the inaugural NEDA Medal by the National Ethnic Disability Alliance and by invitations to present her research findings to global forums including the United Nations (2015 Conference of States Parties to the CRPD – DESA/DSPD Forum on Disability and Development; and 2018 Commission for Social Development, 56th Session, New York) and World Bank (2018, World Report 2023).



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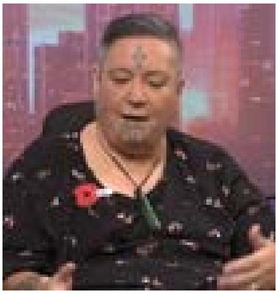
Dr. Nirmala Erevelles is a Professor of Social and Cultural Studies in Education at the University of Alabama. Her teaching and research interests lie in the areas of disability studies, critical race theory, transnational feminism, sociology of education, and postcolonial studies. Specifically, her research focuses on the unruly, messy, unpredictable, and taboo body – a habitual outcast in educational (and social) contexts. Her book, *Disability and Difference in Global Contexts: Towards a Transformative Body Politic* was published by Palgrave in November 2012. She is currently working on a book-length manuscript tentatively entitled *Cripping Empire: Theorizing Intersectionality as if Black/Brown/Disabled Lives Matter.*



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Huhana Hickey (PhD in Laws and kaupapa Māori) has a long-standing interest in the human rights of people from marginal backgrounds and the consequences of discrimination and social oppression. She is a scholar of disabilities research and legal theory and is noted for the breadth of her published cross-disciplinary research. One of Huhana's goals is to increase the knowledge of

Indigenous peoples with disabilities along with increasing their profile and inclusion in all levels of society. Dr. Huhana is a former Director on the HCNZ board (2018–2019), on the Human Rights Review Tribunal (2010–), was an Advisor to the welfare expert advisory group (2018), has her own consultancy (Pukenga Consultancy), is President of the Māori Women's Welfare league Te Hokinga Mai branch for Disabled Māori women, is a former Chair of the Medicinal Cannabis Awareness NZ Trust (2017–2019), and is a partner, Mum, Nana, and keen singer, writer, and poet.

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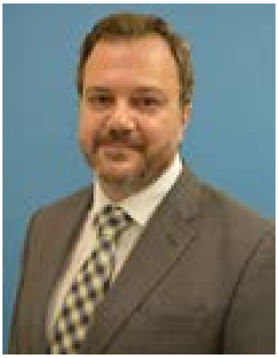
Rados Keravica is a doctoral candidate at the University of Leeds, Centre for Disability Studies in the School of Sociology and Social Policy. He currently works as a Qualitative Researcher at the Bradford Institute for Health Research. He worked as an EU Marie Sklodowska-Curie Research Fellow within the Disability Advocacy Research in Europe (DARE) project at the University of Leeds between 2019 and 2022. His PhD research work focuses on disabled children's participation in healthcare decision-making. He worked previously for the UN Human Rights Team in Serbia as a Disability Specialist where he coordinated the joint UN project aiming to reform the legal capacity regime in Serbia and to support the rights of women and girls with disabilities and employment opportunities for persons with disabilities. He holds an MA degree in Human Rights Law from the Central European University, Budapest, as well as an MSc degree in International Economics from the University of Novi Sad, Serbia. In the period 2011–2016, he worked for Disability Rights Promotion International, a global collaborative project on disability rights monitoring as a Regional Officer for Europe. He serves as a Board Member of the European Network on Independent Living (ENIL).



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Roberto Lattanzio is the Executive Director of ARCH Disability Law Centre. Robert has been Executive Director since 2015, and first joined ARCH in 2003. He has acted as legal counsel in test case litigation at all levels of court, including the Supreme Court of Canada, and has made law reform submissions to various levels of government, committees, and administrative bodies. Robert has been appointed to numerous advisory committees and has written and guest-lectured on diverse topics including equality and human rights law, administrative law, education law, capacity and supported decision-making, disability rights, legislative reform, and social science evidence. Robert received his LLB and BCL law degrees with distinction from McGill University in 2003.

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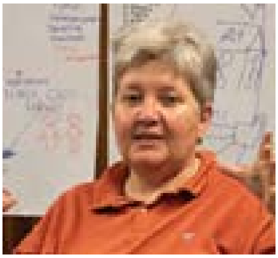
Anna Lawson is a Professor of Law at the University of Leeds where she has just completed an 8-year term as Joint Director of the University's Centre for Disability Studies. Her work focuses on disability equality and human rights at international, national, and local levels. Herself disabled, Anna has played active roles in a range of disabled people's organizations and human rights organizations. She is a Fellow of the British Academy and the Academy of Social Sciences, patron of the National Association of Disabled Staff Networks, and an Honorary Master of the Bench at the Middle Temple Inns of Court, London.



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Theresa Lorenzo is a Professor of Disability Studies and Occupational Therapy, and Co-Director of Inclusive Practices Africa, in the Department of Health and Rehabilitation Sciences, Faculty of Health Sciences, at the University of Cape Town, South Africa. She co-led the development of the first Disability Studies postgraduate program in Africa, in collaboration with Disabled People South Africa and the Centre for Disability Studies at the University of Leeds, which was launched in 2003. She has focused much of her work on collaborative research with non-government organizations and disabled people's organizations to develop reciprocal capacity of a community-based inclusive development workforce for monitoring disability inclusion in policy implementation and practice. One of her strengths is developing innovative research methodologies for data gathering with collectives and groups. She is active in the African Network for Evidence of Action on Disability (AfriNEAD), the CBR Africa Network, and the Occupational Therapy Africa Regional Group (OTARG).

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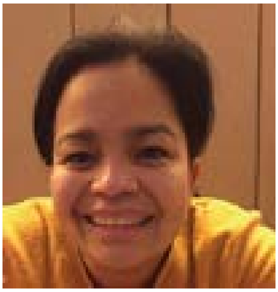
Marina Morrow is a Professor at the School of Health Policy and Management in the Faculty of Health at York University. In her work, Marina uses critical mental health and intersectional approaches to better understand the social, political, and institutional processes through which health and mental health policies and practices are developed and how social and health inequities are sustained or attenuated for different populations. Prof. Marina strongly supports public scholarship and the work and activism of the Mad movement and Mad scholars. Prof. Marina is the Lead Editor (with Dr. Halinka Malcoe) of *Critical Inquiries for Social Justice in Mental Health* (University of Toronto Press, 2017) and lead on the Realizing Human Rights and Social Justice in Mental Health project (www.socialjusticeinmentalhealth.org).



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Dr. Silvia Margarita Baldiris Navarro graduated from the Industrial University of Santander (UIS) in Colombia as a systems and industrial engineer. Later she completed master's studies in Computer Science and Industrial Automation at the University of Girona, a university where she also completed a doctorate in technology. She is currently an Advisor to the Government of Cartagena de Indias, and a Professor at the Fundación Universitaria Tecnológico Comfenalco, Colombia. Her research has always been focused on analyzing how information and communication technologies can facilitate the inclusion of all people in the educational system. She has recently coordinated the formulation of the public policy for Science, Technology and Innovation of Cartagena de Indias, in which she has promoted an inclusive approach, which has considered the participation of all the populations of the region. She has coordinated and participated in international projects and initiatives in Europe, North America, and also in Latin America.

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Dr. Victor Santiago Pineda is a human rights expert, scholar, investor, and philanthropist. His work focuses on inclusive and accessible smart cities. A two-time presidential appointee on the US Access Board, a senior

Fellow at the Mohammed Bin Rashid School of Government in Dubai, and the Chairman of The Victor Pineda Foundation/World ENABLED. His foundation supports global non-profits and campaigns, promoting the rights of people with disabilities and older persons. Dr. Pineda's research and humanitarian works advance urban resilience, inclusion, and sustainability both at home and abroad. Dr. Pineda is an urban planner and a leading scholar on inclusive and accessible smart cities. He directs the Inclusive Cities Lab at the Institute for Urban and Regional Development, UC Berkeley. His teaching and research focus on urban equity, access, and inclusion in global urban governance.

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Paula Campos Pinto holds a PhD in Sociology from York University, Toronto, Canada. She is an Associate Professor in the School for Social and Political Sciences at the University of Lisbon (ISCSP-ULisboa), where she also founded and coordinates the *Observatory on Disability and Human Rights* (OODH), a platform that brings together academics, disability organizations, and decision-makers to support disability research and advance disability rights in Portugal (http://oddh.iscsp.ulisboa.pt/index.php/en/). From December 2016 to March 2021, she was the Chair of the National Independent Mechanism for Monitoring the Implementation of the CRPD in Portugal.

Prof. Pinto has been the principal investigator and researcher in numerous national and international projects related to disability, gender, social policy analyses, and the impact of policy on people's lives and has authored many national and international publications on these topics, including books, edited books, and articles in peer-reviewed journals as well as conference presentations, many of whom as invited keynote speaker.

Gerard Quinn
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Gerard Quinn was appointed the UN Special Rapporteur on the rights of persons with disabilities by the Human Rights Council at its 45th session, in October 2020. Gerard held two research chairs at the Raoul Wallenberg Institute on Human Rights in the University of Lund (Sweden) and Leeds University (UK). A graduate of Harvard Law School, the King's Inns (Dublin), and the National University of Ireland, he formerly held a chair at the National University of Ireland where he founded and directed the Centre on Disability Law and Policy. In Ireland, he served as a member of the Commission on the Status of People with Disabilities (1992–1996) which was composed of a majority of persons with disabilities. This Commission produced an early blueprint for change in Ireland based on equality. He was Director of Research at the Government's Law Reform Commission (1997–1998). He was a member of the Irish Government Taskforce on the individualization of budgets and services (2017–2018). He served two terms on Irelands' Human Rights Commission. At the invitation of the President of Ireland, he served on the Council of State (Ireland) from January 2012 to 2018. He is also currently a Professor Emeritus of law at the National University of Ireland (Galway).

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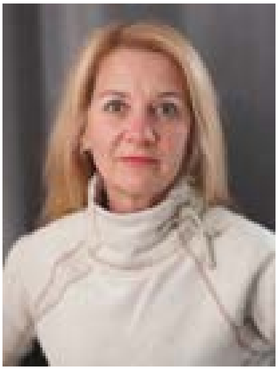
Geoffrey Reaume is an Associate Professor in the Critical Disability Studies program at York University, Toronto, Canada, where he teaches a course on disability history. He established the first university credit course on Mad People's History beginning in 2000.



Vera Roberts
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Dr. Vera Roberts is a leading expert in inclusive design and participatory research, with 25 years of experience in the field. She is the Senior Manager Research, Consulting and Projects at the Inclusive Design Research Centre (IDRC) of OCAD University, where she also teaches research methods for graduate studies. She holds a PhD in Applied Cognitive Science from the Ontario Institute for Studies in Education at the University of Toronto. Dr. Roberts has been involved in numerous multi-partner inclusion projects that leverage inclusive technology and digital sharing platforms to create a culture of inclusion. Some of these projects include: Regulating the Digital Domain, Communication Access, *We Count, Future of Work and Disability*, *Equitable Digital Systems*, *Morphic, BIG IDeA,* and *Our Doors Are Open*. Dr. Roberts provides consulting and training on inclusion and diversity to various public and private sector organizations.

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Sara Scalenghe teaches at Loyola University Maryland in Baltimore, USA. Her research and teaching interests revolve around the global history of disability, especially in the Middle East and North Africa. She is the author of *Disability in the Ottoman Arab World, 1500–1800* (Cambridge University Press).

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Jutta Treviranus is the Director of the Inclusive Design Research Centre (IDRC) and a Professor in the Faculty of Design at OCAD University in Toronto (http://idrc.ocadu.ca). Dr. Treviranus established the IDRC in 1993 as the nexus of an open growing global community that proactively works to ensure that our digitally transformed and globally connected society is designed inclusively. She has emphasized the existential importance of including and valuing people who are currently excluded outliers and small minorities. Dr. Treviranus also founded an innovative graduate program in inclusive design at OCAD University. Dr. Treviranus is credited with developing an inclusive design methodology and inclusive co-design practice that has been adopted internationally.

Stefan Tromel
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Stefan Tromel Since August 2013, Mr. Tromel has been the Senior Disability Specialist at the International Labour Organization. Between 2008 and 2013, he was the Executive Director of the International Disability Alliance and between 1999 and 2004, the Director of the European Disability Forum (EDF). Mr Tromel was actively involved in the negotiation process of the UN Convention on the Rights of Persons with Disabilities from 2002–2006.

Margaret Wazakili
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Dr. Margaret Wazakili is a Holistic Physiotherapist, Disability Consultant, and Managing Director of the MagWaz Physiotherapy and Wellness Services. She obtained her PhD at the University of the Western Cape, South Africa, in 2008, focusing on Disability, Sexuality and HIV/AIDS among young people with physical disabilities. She undertook a 1-year Post-Doctoral Research Fellowship on knowledge and skills needed to combat HIV/AIDS in a workplace and then a 3-year Post-Doctoral Fellowship with Stellenbosch University, Centre for Rehabilitation Studies, working on the African Policy on Disability and Development project. She has taught Community-Based Rehabilitation nationally and internationally as well as supervised Master students in Disability and Rehabilitation studies. She is often asked to mark Master's and PhD dissertations on disability and rehabilitation.

Dr. Wazakili was the first International Joseph P. Kennedy Jr. Foundation Fellow in Africa, working on Disability and Public Policy, as it affects children and adults with intellectual disabilities. She has published her work in accredited journals and presented at a number of local and international conferences as well as carried out disability consultancies in the region.

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Part I

Introduction, Prominent Figures, and Voices of Impact

Nothing Without Us: Disability, Critical Thought, and Social Change in a Globalizing World

1

Alexis Buettgen and Ezra Zubrow

Contents

Abstract

This introductory chapter has been titled: “Nothing Without Us” to reflect our shared belief that inclusion requires much more than changing people with disabilities. This motto has changed a little from the usual rallying cry of the disability movement. It is about shifting, rethinking, and adapting situations and environments to enable inclusion of people with disabilities. It is not enough to only worry about people with disabilities – the shift must be to remedy all societies that exclude people. This chapter provides an overview of the origins of the Handbook and ideas behind it; the evolution of critical disability advocacy,

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scholarship and education programs; and suggestions on how to read and access the contents within the 92 chapters that comprise this volume.

> Disability is not measles. (Rioux, 1994)

> The primary goal of a human rights approach to disability is the achievement of individual autonomy to the greatest extent possible and creation of an inclusive society that respects the dignity and equality of each person. (Rioux, 2004)

> Inclusion: An unending set of processes in which disadvantaged children and adults have the opportunity to participate fully in all community activities available to people who do not have disabilities. (Rioux, 2006)

Introduction

The reason we have named this introduction "Nothing Without Us" is to reflect our shared belief that inclusion requires much more than changing people with disabilities.[1] This has changed a little from the usual rallying cry of the disability movement. It is about shifting, rethinking, and adapting situations and environments to enable inclusion of people with disabilities. It is not enough to only worry about people with disabilities – the shift must be to remedy all societies that exclude people. To make this happen there must be broad systemic changes to the structure of society itself. It is not just about disability but is about fairness and equality on the one hand, and inclusion and accessibility on the other. We need a new era.

This handbook maps the terrain of disability, the world over, by providing an overview of issues, concerns, and developments in various domains. They are advocacy, education, medicine, law, policy, research, disaster management, development, economics, employment, science, technology, history, culture, and society. Working from this interdisciplinary matrix, the book aims to:

- Present an overview of the field of global disability studies in a world-wide and transnational perspective
- Explore the evolution of the concept of disability over space and time
- Identify various approaches to disability and debility
- Highlight broad trends in research on disability across the world
- Identify new directions in practice
- Recognize the emergence of a global disability movement and its etiology

The target audience for this volume are students, scholars, medical, and paramedical professionals, activists and advocates, researchers, international development workers, and others. The editorial team are eminent disability scholars and advocates located across the globe who bring rich professional experiences and unique expertise to guide this work from its inception to completion.

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[1] We use the terms "people with disabilities," "persons with disabilities," and "disabled persons" interchangeably as all terms are used by scholars and activists in the disability movement.

The Handbook contains original pieces on different dimensions of disability by researchers, activists, helping professionals, service providers, international development experts and organizations, professors in disability studies, and policymakers with a particular focus on the voices of the principal stakeholders, people with disabilities themselves.

Origin of the Book and Ideas Behind It. . .

This handbook began around the year 2000 when Bengt Lindqvist and Marcia Rioiux were sitting at Bengt's cottage along the sea watching the water sprites dance. Noting that water sprites were universal, breathing both water and air, they began talking about the need for a book that was equally comprehensive. It should be a discussion of not only the state of disability around the world but aspirational goals.

After Bengt's death in 2016, Marcia secured a book contract in 2017 to fulfill their vision. Marcia's idea for this book was to produce an encyclopedia of the evolution of the field of critical disability (studies). She invited prominent scholars, advocates, and activists from the Global South and North with the intention of presenting a balanced view on critical disability from across all regions of the world. The plan was to create sections led by these accomplished voices and encompassing chapters on substantive topics that highlight the lived experience of disability, the policy environments, and societal attitudes toward disability and people with disabilities. After her death in 2021, the new co-editors incorporated this vision and added emerging scholars in order to include new dynamic viewpoints and rapidly emerging issues in the field. This book is a legacy to both of them.

There were several challenges along the way to completing this project. First, we come from a range of perspectives and disciplines (anthropology, psychology, advocacy, international development, critical disability studies). Second was the death of Bengt, then the death of Marcia. The project was delayed until the new co-editors Alexis Buettgen, Jose Viera, and Ezra Zubrow reinvigorated it in late 2021. The original idea had to be modified because of the changing world conditions as well as logistical issues. However, the editors have tried to remain true to the vision as well as extend it.

Third, the COVID-19 pandemic presented unique challenges for authors and editors around the world – particularly those with disabilities and from the Global South. This presented us with some delays and new opportunities to re-imagine aspects of the book. We worked to provide as much accessibility and flexibility as possible in the development of the chapters and to support the writing process for all. Some authors were coping with the loss of family and friends, civil unrest, office closures, lockdowns, internet failures, as well as increased complications of everyday life under a pandemic. People with disabilities were especially vulnerable because of preexisting impairments, inequities in health care access, the highly contagious nature of the virus and their need for close contact with caregivers, as well as the compounding nature of other forms of social and economic disadvantage. These challenges highlighted the extent to which preparedness and response planning was exclusive and inaccessible to many people with disabilities. We acknowledge and aim to address these barriers.

The Handbook emphasizes calls for inter- and transdisciplinary approaches, alliances, and coalition building. The editors recognize the challenges of alliance building – including the power of non-disabled people, caregivers, and families, as well as the influence of fields outside disability studies.

There are topics that are not included in this book as originally proposed by Marcia. The original project had sections dedicated to quantitative research and disability across the life cycle. It was to have an equal balance of section editors from the Global South and North. We made strong efforts to realize this proposal; however, the challenges noted above in the book building process made this difficult to realize. Alexis, Ezra, and Jose alongside the sub editors worked together to reorganize several of the sections. The following original topics were interspersed throughout the book:

- Inclusive education and learning
- Disability, development, and inclusion in a globalizing world
- Science and culture
- Disability arts and literature
- Innovation and new ideas of inclusion

Other limitations that we recognize include issues regarding open access and language translation, and there may be accessibility issues caused by press limitations. We asked for the book to conform to the Marrakesh Treaty which makes the production and international transfer of adapted books for people with blindness or visual impairments easier. It does this by establishing a set of limitations and exceptions to traditional copyright law.

Further, much of the writing uses academic language and the orientation tends to be overly theoretical and methodologically verifiable rather than oriented to real-world implementation. However, all section editors have made significant efforts to invite and include authors from outside of academia including activists, artists, advocates, and community-based researchers.

This book is part of a rapidly growing body of knowledge and scholarly and gray literature on the topic of disability. This is exemplified by over 7000 serials on the subject, and over 170,000 books. These texts have presented a range of perspectives from various conceptual paradigms of thought and action on disability. An increasing number of these texts are from a disability studies perspective. Moreover, there is a rise in the profile of disability in the humanities. An escalation of multimedia such as disability blogs, creative productions, etc. has meant that the perspectives of people with disabilities have become more accessible to a wider global audience and embedded in various portrayals and mechanisms to continue to organize the movement for transformative social change. The result of this greater visibility is being seen everywhere including from Bollywood to Hollywood. Most recently Coda received three academy awards – namely, Best Picture, Best Supporting Actor, and Best Adapted Screenplay.

How did this rapid growth come about? It was through a long and gradual evolution of the concept of disability, the increase of advocacy, and new international, national, and community policies and laws.

Evolution of Critical Disability

Disability inclusion is evolving both conceptually and operationally in societies. One way to examine the historical change in both the thinking and activity regarding disability is through a set of paradigm shifts (Kuhn, 1970). Over the last century, disability has been understood through paradigms that have changed both thought and action. Each has been pervasive for certain times, locations, and cultures.

It is imperative to examine multiple understandings of a particular social phenomenon such as disability. This examination should include careful consideration of how constructs and measures systematically include and exclude certain understandings of disability to serve the political interests of some groups at the expense of others.

Being able to understand where we were, where we are, and where we need to be allows us to focus on change as a process, rather than a destination. The disability movement is one that has grown out of people who looked for solutions to what limited them in their own lives, and then taken that forward. The historical lack of free decision-making by people with disabilities motivated the need for people with disabilities to be leaders of the change they wanted to realize.

There are tensions within the movement because it is a social and political movement that reflects the diversity of disability. The movement includes different interests in money, power, political orientation, and reputation. This is particularly critical as we are living in turbulent times and facing social, economic, and environmental crises that will impact the lives of people with disabilities. This means that the movement is tasked with creating opportunities for inclusion, solidarity, and collaboration while ensuring that progress made is not lost.

Turning to the intellectual history of the movement, there are four paradigms that can be distinguished. Namely, the medical paradigm, the social paradigm, the human rights paradigm, and the disability justice paradigm.

Medical Paradigm

The first paradigm is defined by what has come to be called the “medical model” sometimes called the “individual model.” Underlying its general theory and methodology is the belief that disability can be corrected by diagnostic tools to identify pathology and develop medical and individualized interventions to cure or minimize it. The use of charity and rehabilitation approaches fall under this model.

Criticisms of the model are based on the failure of medical and other professionals to involve people with disabilities in a meaningful way except as passive objects of intervention, treatment, and rehabilitation. According to Michael Oliver (1990), under this model most research and the development of knowledge on disability has been exclusive and non-participatory. Thus, the medical model has had oppressive consequences for people with disabilities because it focuses on an individual's limitation(s), deficiencies, deviance from the norm, and overall challenges to fit into society. Solutions are focused on ways in which to "fix" an individual to better fit into society, rather than how society can better accommodate difference.

Historically, the social response to disability has been managed by separation, segregation, and incarceration of people with disabilities, particularly since the onset of industrial capitalism. This response is reflected in practices of special education, building of asylums, medical classifications, and sheltered employment. (One of the building blocks of current thinking on disability is based on the need to overcome such segregation through the enactment of human rights, as well as programs, policies, and laws that reflect the principles of inclusive education, affirmative action, reasonable accommodation, supported decision-making, and inclusive design. This current thinking is particularly prevalent in the area of employment and education where a business model influences employers and educators to see opportunities for the employment of disabled persons as assets rather than liabilities in many sectors of the neo-liberal economy.)

Given the development of major medical practices, pharmaceutical solutions, and medical equipment for people disabilities, there has been strong economic and financial reasons to continue this model. Medical institutions (broadly defined) have resisted intellectually, politically, and economically the change to another paradigm (Evans, 2004; Foucault, 2006; Oliver, 1990; Szasz, 1974).

Social Paradigm

The second paradigm is the "social model." The social model developed in response to the medicalization and individualization of disability in the preceding medical/individual models. Pioneered by British activists after its development by Oliver (1990), this critical Marxist approach to disability issues has become internationally influential. Most importantly it changed the way people with disabilities see themselves and organize for social change. According to the model, disability is a social construction, and the vast experiences of physical, mental, and sensory impairment are not reduced to medical diagnoses, pathologies, and diseases but are instead placed in the social and cultural contexts of their times.

In the social model, disability is defined by the lack of participation and access in society. The model differentiates "disability" from "impairment" whereby disability is a consequence of the way society is organized, rather than a person's impairment or bodily difference. The model begins with a definition of impairment as "lacking all or part of a limb, organism or mechanism of the body" (Oliver, 1996, p. 22), which also includes psycho-social, intellectual, and sensory impairments. Disability then is created by a society that limits and restricts the full participation of impaired people. The social model seeks to change society to accommodate and include people living with impairments. It does not seek to change people with impairments to accommodate or be included in society. This model changes the focus of the problem of disability away from the impaired individual and places it directly onto societal norms, practices, and structures. In comparison to the medical model, this approach focuses on the social, attitudinal, physical, and environmental barriers that restrict the life choices and participation of people with disabilities. In this way, all society needs to do is to accommodate and include people with disabilities.

Human Rights Paradigm

The third paradigm is the human rights paradigm. As the social model has developed over the past few decades, there has also been a rise in the profile of disability rights at the national, regional, and international levels. The human rights model defines disability in accordance with the United Nations Convention on the Rights of Persons with Disabilities (UN General Assembly, 2007) as, "long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder [an individual's] full and effective participation in society on an equal basis with others" (p. 4).

The CRPD was adopted in 2006 at the UN following decades of work to change attitudes and approaches to persons with disabilities. The Convention was negotiated by a committee of various state governments, relevant bodies and organizations of the UN system, as well as intergovernmental and nongovernmental organizations including individuals and organizations of persons with disabilities (OPDs). It was negotiated during eight sessions between 2002 and 2006, making it the fastest negotiated of all human rights treaties. Similarly, once established, the Convention became the most quickly supported human rights instrument in history. There were 160 States that signed the Convention on its opening day in 2007 and 126 more States ratified the Convention within the next 5 years. The reader should know that ratification of the Convention means that the signatory states accept legal obligations to enact the necessary legislation required by the CRPD.

The Convention marked a shift in views on disability from a social welfare to a human rights issue. It took the movement to new heights with a profound shift toward viewing persons with disabilities as holders of rights, "who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society."[2] People with disabilities should no longer be viewed as objects of charity and medical intervention.

The Convention is a human rights instrument with an explicit, social development dimension. It adopts a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. On the positive side, it clarifies and qualifies how all categories of rights such as employment and education apply to persons with disabilities. Furthermore, it identifies areas where adaptations have to be made for persons with disabilities to effectively

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[2] https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd

exercise their rights. On the negative side, it identifies areas where their rights have been violated, and where protection of rights must be reinforced.

The human rights model conceives people with disabilities as diverse rights-bearing citizens and embraces substantive and transformative conceptions of equality that address the physical, economic, institutional, and social barriers that undermine their rights and dignity (Degener, 2016). This model is inspired by the values of dignity; autonomy; participation, inclusion, and accessibility; non-discrimination and equality; and respect for difference. This perspective also considers the multiple identities that people with disabilities hold, and intersecting forms of oppression related to their sex, gender, age, race, or other characteristics. Finally, a disability rights perspective focuses on the barriers that people with disabilities face in society and the legal and policy solutions through which they can be dismantled.

According to Quinn & Degener (2002), the human rights paradigm for people with disabilities considers "Each individual is deemed to be of inestimable value and nobody is insignificant. People are to be valued not just because they are economically or otherwise useful but because of their inherent self-worth" (p. 14). This means that people with disabilities have a stake and claim on society regardless of considerations of economic or social utility. As we will see later, there are critiques regarding the over-individualization of some aspects of the human rights paradigm and lack of causation of the root causes of exclusion.

The UN from its origin has played a pivotal role in raising the issue of disability rights at the international level in terms of laws, aspirational policies, operational programs, and local interventions. For example, at the international level, the formulation of the CRPD and the explicit positioning of disability in several of the Sustainable Development Goals are critical frameworks that situate disability at the interstices of the global and the local. At the national and local levels, there is increased recognition of the need for inclusion of the voices of people with disabilities in the design and implementation of community-based rehabilitation programs and the International Labour Organization disability employment initiatives. Moreover, the World Report on Disability (World Health Organization & World Bank, 2011), and the International Classification of Functions, Disability and Health (ICF) – albeit imperfect – are standardized resources on disability and are used worldwide. In the human rights model, ultimately, the positioning of disability is not only a critical issue that situated disability at the interstices of the global and the local but it is positioned as an intrinsic aspect of every person with or without disabilities.

Disability Justice Paradigm

The fourth paradigm is the disability justice paradigm. This paradigm is the next and contemporary stage in the evolution of the disability movement. Originally envisioned in 2005 by disabled queers and activists of color (Sins Invalid, 2020), this developing framework is being created as this volume is being published. In contrast to the human rights model, this paradigm points out that human rights frequently are so generalized that they are not operational for specific issues or specific marginal groups. Disability justice is the framework of the social movement to end ableism in conjunction with ending other systems of oppression. Disability justice commits to collective access to “create and explore new ways of doing things that go beyond able-bodied/minded normativity” (Berne et al., 2018, p. 228) in various spaces and places and in social movements. As a theory it offers opportunities for movements to connect, this explicitly intersectional paradigm provides a framework for understanding social justice, racial justice, and disability justice. They are not separate but rather interconnected and at times the very same matter (Jampel, 2018).

The principles of disability justice begins with intersectionality promoted by leadership of those most impacted by systems of oppression and violence. It is informed by an anti-capitalist politic, a commitment to cross-movement organizing and cross-disability solidarity, interdependence, collective access, and liberation and a focus on sustainability of the movement.

Prior to the disability rights movement, if people with disabilities were mistreated, there were no legal repercussions. Most spaces and places were not accessible and it was expected that disabled people would not participate in society. For example, one may consider the famous case of the paraplegic Charles Lane who was forced to crawl up the stairs in Tennessee to reach a hearing on the second floor regarding denial of accessibility for people with disabilities in state courts. A disability justice framework understands that all bodies are unique and essential, have strengths and needs that must be met, are powerful because of their complexities and confined by ability, race, gender, sexuality, class, nation state, religion, etc. and we cannot separate them (Sins Invalid, 2020). It focuses on the causation of exclusion and marginalization rather than focusing on rectifying laws and policies.

We found that in the sense of the Kuhnian long run, these paradigms have partially replaced each other in a dialectic synthesizing the best of each as they change and evolve. However remnants of each continue to exist with what can best be described as a checkered pattern across the global north and south.

Disability Studies Programs

Disability has long been studied in universities and hospitals but primarily from a clinical, psychological, or sociological perspective that framed disability as deviance. The field of disability studies emerged from the activism of people with disabilities in the 1970s and became an independent academic field in the 1980s (Rawson, n.d.). The field emerged primarily in the USA, the UK, and Canada and has diffused now globally. It was inspired by the social model of disability such that, “Scholars and researchers began to think of disability as a social construction and a set of cultural products, and of disabled people as a group historically oppressed but politically recognized under the logic of civil rights” (Garland-Thomson, 2013, p. 916). The first disability studies program was developed in 1996 at Syracuse University (https://soe.syr.edu/disability-studies/) and by the end of the 1990s, it had become a widely recognized field of study in which aspiring academics could publish, conduct research, and teach in formally employed positions.

Currently, there are hundreds of disability studies degrees and courses around the world. In 2009 *Disability Studies Quarterly* published a multinational review of English-language disability studies degrees and courses. They found that the field is expanding at an exponential rate with three key dimensions of growth in independent disability studies departments, hybridization with applied disciplines, and integration within the liberal arts (Cushing & Smith, 2009).

Critical disability studies is a complex, interdisciplinary field of study. It is rooted in activism, radical hope, a commitment to critical theory and has its own fair share of internal debates. For example, because disability is a historically and culturally contingent and contested social category, it is surprisingly difficult to define. Definitions vary by country. Some states have disability laws and policies that include people with mental health labels, while others do not. Anti-psychiatry, ex-patient, and Mad movements have only recently been included in disability movements. Women and trans-people struggled for a long time to get people with chronic illness recognized as part of the disability community (Buettgen & Gorman, 2019). Disability justice activists have also struggled to make space for disabilities that are disproportionately experienced by Black, Indigenous, and people of color, including conditions related to environmental toxicity, war, and experiences of violence, exploitation, and racism.

Some argue that the term “disabled people” emphasizes that disability is an essential part of self-identity. Others argue that the term “people with disabilities” or “persons with disabilities” puts people and the individual first and that disability is only one aspect of overall identity. None of these terms are universally accepted, “but the very fact that this debate exists reflects the efforts of a long-marginalized community to assert how they should be defined on their own terms” (Reaume, 2014). Thus, the field is by, and not just about, people with disabilities and centers their interpretation of their place in the world based on a social and political definition rooted in societal power relations.

Critical disability studies considers how institutions and societies systematically “dis-able” people. This area of study involves both academics and activists representing multiple disciplines and perspectives. Frequently disability studies programs in universities or colleges are connected either within the department or within a semi-independent research institute. Only recently have they become departments in their own right. As in the case of many emerging fields there is no standardized curriculum and most departments are crafted from the viewpoints and faculty interests of the institution. This has several consequences. First, it means that a student who wishes to “do disability studies” will usually know who the faculty are and what type of curriculum they will encompass. Second, because it is not standardized it means that students with the same degree may have had very different training and interests. Third, it means that there are various career paths followed by graduates depending upon which institution one attends. In short, it is an exciting field of study but not a career path for the faint of heart.

Disability studies lends credibility to the social, human rights and disability justice model. It establishes these models as a legitimate field of study and profession. Although not all faculty and staff in disability studies are disabled, many of these programs and institutions provide an intellectually stimulating place to grow and learn from their own or others' lived experiences.

There is a wide spectrum of programs that reflect the evolution of the paradigms of disability. Some programs lean more toward the medical model, some lean toward the human rights model, and some are firmly embedded in the disability justice model. As in other fields, the friends, colleagues, and relationships that are developed in these programs frequently last lifetimes and entire careers. There are overlapping networks that originate in these programs that impact the formation of government policies, court cases, and even benefits in a way that would not have been 30 years ago.

In conclusion, the field of disability studies, although still emerging is relatively rare. There are too few programs in either the Global North or Global South given that people with disabilities are the largest minority group worldwide. Those few programs that exist are still sometimes marginalized but are beginning to take their place among other more established departments.

About the Handbook

The editorial policy of this book is to take a broad view of critical analysis – one that is broader than postmodernism, poststructuralism, psychoanalytic criticism, and Marxism. Here we focus on the pragmatics of critical theory and fundamental thinking about criticality and disability.

Critical theory is useful to the field of disability studies as an interdisciplinary school of thought striving toward emancipation. This theoretical perspective focuses on the possibilities for transformative change by exposing and challenging the institutions and mechanisms of domination and power. Critical theory provides a method for analysis of the many forms of domination that inhibit radical transformation and political movements.

This handbook highlights forms of domination that are often hidden and must be unmasked to develop alternative socio-political-economic systems that promote well-being rather than serve the interests of capital. It is intended to support work that unleashes the potentialities of all human beings, links theory, and practice and engagement in participatory processes. In this sense, critical theory is helpful to our understanding and re-conceptualization of disability. Critical theory is anti-oppressive, anti-positivist, and anti-capitalist which align with the values of many disability studies scholars. One needs to understand how socio-political-economic systems such as capitalism, colonialism, and fascism have uniquely *dis*abled people from full participation in society.

We follow in the footsteps of Marcia Rioux claiming that critical theory matters because the development of theory associated with disablement and equality impacts our collective understanding of the meaning of disability. Furthermore, it impacts the development of laws, policies and practices (Rioux & Valentine, 2006). A critical disability theory approach offers an important lens in unraveling the inherent complexities associated with disability and equality/inclusion. For example, one of the General Principles of the CRPD (developed by and for persons with disabilities around the world) includes respect for inherent dignity, individual autonomy, and the freedom to make one's own choices. The principles also emphasize respect for difference and acceptance of persons with disabilities as part of human diversity and humanity. These clearly are derived from the application of critical theory.

The disability rights movement and emerging discipline of disability studies have challenged the medical model that characterizes disability as a physical and mental defect that can be cured or managed at an individual level through medical interventions. But developments in science and biotechnology are re-igniting the medicalization debate or what is now being called the re-medicalization of disability. Genetic research, and particularly genetic selection, is posing dilemmas to the meaning of disability in society. This issue will be covered across several sections including the section on ethics.

Through the text, key concepts of accessibility, inclusion, and inclusive design will be described and debated. The concept of inclusive design considers the full range of human diversity with respect to ability, language, culture, gender, age, and other forms of human difference. It recognizes the interconnectedness of users and systems moving beyond the notion of separate, specialized, or segregated solutions. In this way, disability is framed as a mismatch between the needs of the individual and the design of a product, system, or service. With this framing, disability can be experienced by anyone excluded by design which, to overcome, requires the integration of inclusive design and generic design. While universal design has its origins in architecture and industry, it is now included in the digital realm – which requires flexibility, adaptability, and personalized approaches to inclusion. Chapter authors will examine these issues in a variety of contexts throughout the volume.

The introduction of new ideas about the meaning of inclusion, equality and equity, and the right to be different opens up new avenues for a perspective on disability. These new ideas move us to a better understanding of fundamental issues such as supported decision-making and labor market initiatives that go beyond policy, programs and thinking on disability. With the introduction of these new ideas in the various sections, we collectively (in collaboration with chapter authors and section editors) open up emerging, hitherto unimagined areas in which the disability paradigm is integrating and impacting many areas of social, economic, and political life.

The majority (80%) of persons with disabilities live in the Global South. This includes low- and middle-income countries. However, the bulk of the literature in the field of disability studies is from the Global North. We believe that this reflects an imbalance of power and access to knowledge. Thus, we have made a significant effort to include authors and editors from the Global South to raise the profile of the lived experiences, challenges, barriers, and opportunities facing people with disabilities around the world.

How to Read and Access the Book

This handbook does not need to be read in either chronological or spatial order. It is an encyclopedia of knowledge and resources intended to support the progressive realization of human rights and pursuit of social justice. Encourage people to reach out to us, the section editors and authors to connect, ask questions and dialogue, and share knowledge and resources.

Each section includes an introduction by each section editor to provide reflections on the past, present, and future of their respective areas of expertise and a summary of the chapters in their section. They also provide a context in which to place their chapters while the editors in chiefs' introduction and conclusion provide an overall context for the state of disability studies, advocacy, and movements worldwide.

The Handbook contains original pieces on different dimensions of disability by researchers, activists, helping professionals, service providers, international development experts and organizations, professors in disability studies, and policymakers with a particular focus on the voices of the principal stakeholders, disabled persons themselves. Section editors have been identified with dedicated effort to include editors from the global North and the global South.

The field of disability studies will be examined from a variety of perspectives as described in the overview of sections below. The Handbook also includes an index of terms for easy access to particular subjects and keywords.

Overview of Parts

Part I is a collection of prominent figures who have had voices of impact. These voices raise core issues that have influenced our understanding and approaches to disability over time. This section reflects on the twentieth and twenty-first centuries and offers some predictions about future directions. It segues into the history of disability rights.

Part II covers the history of the development of the disability rights movement as well as the history, ideas, and ideology of disability from different parts of the world. The section includes chapters from authors in different areas of the world and from different religious perspectives. In order to organize these diverse views the next section coalesces these into paradigms.

Part III addresses disability paradigm shifts, describing current models, perspectives, and philosophical orientations that drive and determine the responses to disability globally and locally. It explores models/perspectives that emanate from presumptions of individual pathology in contrast to those that emanate from presumptions of socio-political factors. These paradigm shifts are inextricably linked to the evolution of the field of critical disability studies as described the next section.

Part IV looks at critical disability studies as a consolidating field. A form of knowledge production, "critical disability" deals with what is between, through, and beyond any discipline. It recognizes and accounts for complex theory in social disciplines. Specifically, this section outlines and problematizes the social determinants of disability, and ways of addressing those within an academic discipline. It takes a cross-section of work in the emerging discipline of disability studies to highlight the importance of understanding what each discipline brings to disability studies. One area where the cross sectional and transdisciplinarity discussed in this section is applied is in various approaches to the study of disability which is taken up in the next section.

Part V on research examines approaches to the study of disability including decolonizing methodologies, biological, survey, ethnographic, feminist, and post-modernist epistemologies and methodologies and will be grounded in the concept of emancipatory research to studying disability will be prevalent here. The next section explores these intersectional approaches further focusing on diverse disability identities.

Part VI on Intersectionality focuses on diverse disability identities located at the interstices of caste, class, gender, sexuality, and indigenous peoples. This section highlights the experiences of persons with disabilities within other marginal identities before moving into discussions of monitoring and indicators of disability in section seven.

Part VII, Monitoring and Indicators of Disability Rights, identifies recent work on indicators for the CRPD, for the SDGS, and for other international instruments. The section directly addresses the understanding of how evidence-based progressive realization can be measured and monitoring advances the implement of progressive realization within the framework of disability and other international instruments. The development of inclusive monitoring tools and indicators requires utilization of the principles of inclusive design and accessibility which is discussed in detail in the next section.

Part VIII is on Inclusive Design and Accessibility. Inclusive design considers the full range of human diversity with respect to ability, language, culture, gender, age, and other forms of human difference. It recognizes the interconnectedness of users and systems moving beyond the notion of separate, specialized, or segregated solutions. Rather than a personal characteristic or a binary state (disabled vs. non-disabled), disability is framed as: a mismatch between the needs of the individual and the design of the product, system, or service. Inclusive design includes digital accessibility and evolving technology. With this framing, disability can be experienced by anyone excluded by the design. The problematic of unequal distribution of inclusive design and inaccessibility can be seen in the experiences of socioeconomic poverty and exclusion of persons with disabilities as discussed in the next section.

Part IX focuses on Poverty and Economic Inclusion to look at the relationship of disability to poverty. There are many themes that poverty and economic inclusion of people with disabilities raise in the context of disability, including theories of poverty; why employment initiatives have failed to reduce poverty for people with disabilities despite the huge local, national, and international development grants that have been invested; local and global approaches to poverty reduction; and the role of the disability movement in poverty reduction and how has this been impacted by the charity perspective, the social model, and the disability rights movement. These issues raise concerns about ethics and the influence of law on the lives of people with disabilities.

Part X moves into Disability, Ethics, and Law. Important issues of trans-humanism, supported decision-making, living wills, euthanasia, dying with dignity, meaning of equality under the law; capacity to consent; right to life (Article 10 of CRPD); non-consensual sterilization; gender identity, sexuality and sexual expression, reproduction, and the future of mental health law are addressed. With these critical concerns in mind, the next section focuses on the implementation of law and policy.

Part XI looks at Implementing Policy and Law from a Rights Perspective to explore and unpack the meaning of human rights. The section includes analyses of the UNCRPD, illustrations of disability legislation post UNCRPD, anti-discrimination legislation, and different rights discourses to provide a context to disability rights. The chapter explores the scope and impact and potential of the CRPD. With the introduction of the CRPD and the SDGs, there is on-going work to develop evidence-based methods of monitoring that incorporate the voices of people with disabilities, a requirement of reporting by countries that have ratified the Convention. Effective implementation of laws and policies often relies on activism and advocacy from the disability movement which will be discussed in the next section.

Part XII focuses on various forms of disability activism from different places in the world that are popping up and taking root. This section includes discussions of self-advocacy and parent-led activism, bullying, oppression, and incarceration; as well as movements guided by psychosocial survivors of psychiatry; people with intellectual disabilities, physical disabilities and sensory disabilities.Activism and advocacy are also critical in the life and death experiences of people with disabilities in disasters and conflict.

Part XIII on Disaster, Conflict, and Environmental Conditions includes an analysis of the impact of natural and man-made disasters and climate change on persons with disabilities as well as disability as a result of war, road accidents, or firearms. The section also includes disaster relief measures designed for people with disabilities.

The concluding part offers insight on ways to move forward, critically engaging in where to go from here given our globalizing world.

It is our hope that this volume opens up an expanded range of issues, insights, and developments in the field of critical disability studies to debate and discuss. We approached this work with the intention that what is offered in the following sections is taken up by scholars, activists, international development works, researchers, and students alike seeking to achieve equality around issues affecting persons with disabilities the world over.

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Marcia Rioux: A Voice for Impact

2

Ezra Zubrow and Alexis Buettgen

Contents

Abstract

This chapter spans the career of Marcia Rioux who was a profound voice for impact and change in the field of critical disability and human rights. Internationally and nationally, Marcia Hampton Rioux was regarded as a leading legal scholar and pioneer in the field of human rights and equity. She was a driving force in the promotion of disability rights and the enhancement of opportunities for marginalized people. She played a leadership role in the United Nations Convention on the Rights of Persons with Disabilities and published widely in the area of disability and human

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rights. Editing a number of collected volumes, she wrote more than 70 book chapters and articles on human rights. Holding a Ph.D. in jurisprudence and social policy from the University of California, Berkeley, she was the director of the Roeher Institute in Toronto, Canada, whose purpose was to secure the inclusion, citizenship, human rights, and equality of people with disabilities. She was the director at York University's Institute for Health Research as well as the cofounder and first chair of the School of Health Policy and Management and the founder of the Critical Disabilities Studies Program. She was a co-founder of Disability Rights Promotion International, which now monitors rights for people with disabilities in more than 62 countries. She held the positions of Distinguished Research Professor and Professor Emerita in the School of Health Policy and Management in York University's Faculty of Health in Canada, and was a Fellow of the Institutes of Advanced Studies in the United Kingdom and Australia. Professor Rioux was the recipient of the Lieutenant Governor's Community Volunteer Award in recognition of her contributions to Ontario communities. In 2014, she was invested into the Order of Canada for her scholarship in the field of social justice and for her advancement of the rights of persons with disabilities.

Introduction

Internationally and nationally, Marcia Hampton Rioux was regarded as a leading legal scholar and pioneer in the field of human rights and equity. She was a driving force in the promotion of disability rights and the enhancement of opportunities for marginalized people. She played a leadership role in the United Nations Convention on the Rights of Persons with Disabilities and published widely in the area of disability and human rights. Editing a number of collected volumes, she wrote more than 70 book chapters and articles on human rights. Holding a Ph.D. in jurisprudence and social policy from the University of California, Berkeley, she was the director of the Roeher Institute in Toronto, Canada, whose purpose was to secure the inclusion, citizenship, human rights, and equality of people with disabilities. She was the director at York University's Institute for Health Research as well as the cofounder and first chair of the School of Health Policy and Management and the founder of the Critical Disabilities Studies Program. She was a cofounder of Disability Rights Promotion International, which now monitors rights for people with disabilities in more than 62 countries. She held the positions of Distinguished Research Professor and Professor Emerita in the School of Health Policy and Management in York University's Faculty of Health and was a Fellow of the Institutes of Advanced Studies in the United Kingdom and Australia.

Professor Rioux was the recipient of the Lieutenant Governor's Community Volunteer Award in recognition of her contributions to Ontario communities. In 2014, she was invested into the Order of Canada for her scholarship in the field of social justice and for her advancement of the rights of persons with disabilities. Professor Rioux lectured throughout the Americas, Europe, Africa, and Asia. She was a visiting scholar and professor at a number of international institutions, including the University of Zagreb, Croatia, and LaTrobe University in Australia. Marcia died in September 2021. Her last project was this handbook.

Early Years

Marcia was born on May 16, 1947, in Trail, British Columbia, Canada. She was the daughter of the late Edouard and Phyllis (née Gray) Gautschi and the youngest of three sisters. Her parents raised them to do service and help others. Her uncle was Hampton Gray – the last Canadian awarded the Victoria Cross. All three sisters earned Ph.D.'s in the health fields. Marcia Rioux spent her entire life working to fulfill those joint ambitions.

After graduating from Carleton University, Marcia began her career as a research assistant at the Royal Commission on the Status of Women in 1968. Six years later, she became the Director of Research at the Canadian Advisory Council on the Status of Women. In the year 1977, she joined the Law Reform Commission of Canada as a Policy Analyst. At that time, the commission was examining issues such as "sterilization of the mentally ill, and personality and behaviour control," as well as euthanasia and sexual offenses (Law Reform Commission of Canada, 1976). These critical issues and work experiences influenced Marcia's thinking about both the status of women and people with disabilities as constructed by laws and policies.

From 1979 to 1986, Marcia worked as a consultant for the Canadian Human Rights Commission; British Columbia Human Rights Branch; Royal Commission on Equality in Employment; National Council of Welfare; and others while completing her Ph.D. in Jurisprudence & Social Policy at Boalt Hall, University of California, Berkeley. Among her professors was Laura Nader who was famous for recognizing "studying up" – the role of impact of the marginalizer on the marginalized.

Marcia's dissertation titled "The Equality-Disability Nexus: The History and Law of Mental Handicap [sic] in Canada" reflected on the history of treatment and legal status of people with intellectual disabilities in Canada as a complex interaction of medical science, technology, economics, law, and politics. It challenged the logic of separation and difference that perpetuated the marginalized position of people with disabilities. She poignantly asked whether difference can form the basis for equality and explored the extension of citizenship rights to persons with intellectual disabilities. She wrote:

> ...[T]he manner in which differential treatment in law and policy of people with mental handicaps has been legitimated...raises the question of whether the nature and type of difference between those with mental handicaps and others justifies the continuing marginalization and denial of a claim to equality and rights. (p. 1)

Marcia proposed an equality of well-being model in which rights would be guaranteed independent of difference and that recognized the need for a range of social interventions to ensure equality. Looking first at history, she claimed:

> Tracing the history of exclusion reveals the social interests that have been served by limiting participation of this group, outlining three identifiable periods of legal and social action.

> . . .[First] in the English Poor Law, aimed to protect society from the differences of those with mental handicaps through policies of confinement, strict state control and a eugenic imperative . . . (second) . . . social attitudes and legal norms based on charity and benevolence. . . (third). . .with the control exercised primarily through medical decision-making and local authorities. (pp. 1–2)

She explicated her model such that:

> The eradication of discrimination against those with mental handicaps [sic] thus requires a more fundamental alteration of the existing legal and social order than does the elimination of race or gender discrimination and even sex discrimination. . . An encompassing model of equality must confront intellectual differences, not ignore them. For this it is not a matter of irrational prejudice focused on superficial differences but the elimination of assumptions about the basis of legitimate claims of people whose salient differences will not diminish. (p. 232)
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> To achieve this form of equality would require the redistribution of state resources to actualize equality of well-being. Mental handicap would no longer be a negative concept, but would denote something positive to which a particular social status was attributed. The granting of entitlements could be attached purely by reason — of an individual's being - independent of their potential to compete. It refocuses the concept of equality, both legally and socially, from the negative notion of "discrimination" to a positive means of integration. . .Setting the equality standard as an outcome measure removes the need for each disadvantaged group to show the discrimination that it had faced and to establish that it can compete in the existing social and economic structure or to show why adaptation should be made so that they can compete. (pp. 234–235)

During and upon completion of her Ph.D., Marcia became a leading proponent of critical thought and inclusive research. Her work made national and international strides toward a paradigm shift in the way societies viewed and treated people with disabilities in order to move away from the medical model toward a rights-based approach.

Mid-Career: Becoming a Thought Leader

In 1987, Marcia became the Executive Director of the Roeher Institute and later became the President until 2000. She led the organization to become renowned in the development and exchange of ideas founded on a new way of understanding disability and society. The institute raised awareness about the barriers that affect people with disabilities and presented critical policy and program alternatives. Over the course of almost two decades, the Institute produced a large assortment of analytical publications, as well as education and training sessions to provide insight into the social policies, laws, and programs that act as barriers to the full participation of people with disabilities in Canada and internationally.

This work included the famously "infamous" book titled: "Disability Is Not Measles: New Research Paradigms in Disability" (Rioux & Bach, 1994). This coedited book critiqued the reification of disability entrenched through a positivist theory of knowledge and focused on the social, economic, political, and legal construction of disability. Returning to the history of research regarding the treatment of people with disabilities (dating back to the 1800s), she guided our collective understanding of why people with disabilities experience profound poverty, violence, marginalization, and exclusion in society.

Bringing the reader up to the present moment at the time, she strongly wrote:

> “What does the preponderance of research in the field look like now? It looks a great deal like the research into measles. The goal is prevention. Consequently, identifying the condition and its biological origins is still a preoccupation of much of the work. Cures are sought - now euphemistically called prevention - and divided between biological prevention and environmental prevention....with new research showing the relationship between such elements as workplace toxins, alcohol use, age of women at conception and rates of disability. (Rioux, 1994a, pp. 3–4)
>
> There is, however, another important policy agenda that must be addressed in the research of the 1990s on disability. The philosophical foundations of notions of citizenship and equality are important to the critique of traditional research in the field. The underlying assumption of the lack of status of persons with disabilities has promoted, or at a minimum left unquestioned, the funding and undertaking of research that would be ethically and legally unacceptable if it involves other groups.
>
> ...Disability is not measles. It is not a medical condition that needs to be eliminated from the population. It is a social status and the research agenda must take into account the political implications attached to that status. (Rioux, 1994a, pp. 6–7)

After the publication of *Disability is Not Measles*, Marcia presented a paper titled “Disability: The Place of Judgement in a World of Fact” at the 10th World Congress of the International Association for the Scientific Study of Intellectual Disabilities in Helsinki, Finland, July 1996 (Rioux, 1996). She critically addressed the impact of economic neoconservatism, the Washington Consensus, and Western utilitarianism as the underlying principles for policy as well as for research and professional practice to reject out of hand, a research culture driven by objectivity and positivism.

Marcia pushed the research community to recognize the forces that shaped the questions they asked and the criteria of validity they adopted in disability research. She wrote:

> Ways of viewing disability, of developing research questions, of interpreting research results, of justifying research methodology and of putting policies and programs in place are as much about ideology as they are about fact. (Rioux, 1996, p. 1)

Within a strong critique of positivist ideology, Marcia contended that:

> [T]he research community in the field of disability has created a world of “disability facts”, but has been relatively unconscious about the judgements it has made in doing so In creating the world of facts, we have assumed that the place of judgement belongs to the advocates, the policy-makers, the politicians, the courts. I think that we need to reconfigure the place of judgement in the world of facts we construct in the field of disability research. (Rioux, 1996, pp. 21–22)

In 1997, she was invited by Michael Oliver to be a fellow of the Institute of Advanced Study at Bristol University, United Kingdom, as the Benjamin Meeker Visiting Professor for 6 months. Although already well known in the field of disability, she was introduced to important policy makers outside of disability in the United Kingdom and Europe. These contacts later became very important in her efforts to reach powerful leaders outside the realm of disability who could influence the progressive realization of human rights. She recognized that they could help her harness the more general agendas of social, political, and economic inclusion and apply them to disability.

One year later, in 1998, Marcia and her colleagues at Roeher put together one of the first articulations of the cost of exclusion of people with disabilities. This work was presented at The World Bank in Washington D.C., March 5, 1998. In front of an audience of powerful international bankers and economists, Marcia presented a speech titled: "Enabling the Well-Being of Persons with Disabilities" (Rioux, 1998). In this speech, she argued that not only was disability internationally conceived expensive, but it was not sustainable. It was a hodge-podge of reactive "shreds and patches." After demonstrating her case, she suggested "a disability paradigms" to introduce coherence and sustainability into World Bank and other international financial initiatives. She argued that a disability framework does the following:

- Recognizes that disability is a result of the biological condition, functional capacity, and social status of the individual.
- Recognizes the broad set of social, economic, legal, and environmental factors which contribute to exclusion and inability to exercise human rights.
- Recognizes the well-being of everyone through a respect for diversity and differences.
- Recognizes that people must be enabled and supported to choose the way in which they want to live.
- Recognizes social justice and the sense of the citizens that they are being treated fairly (unlike the situation now where too many people for one reason or another feel that they are being treated unfairly because of conditions over which they have no control, such as race, sex, color, religion, disability, sexual orientation, and so on).

She believed that one of the great challenges for these institutions was to recognize that incremental reforms and project funding were not ends in themselves. They were simply part of a continuum of change, and while each country will make changes within its own cultural context and economic and social conditions, it is possible that the projects as a whole work together toward that set of broader objectives that ensure inclusion, human rights, and full citizenship.

By this time in the late 1990s, Marcia was increasingly present on the international scene. Marcia was working as a Consultant for the Interregional Seminar and Symposium on International Norms and Standards relating to Disability, organized by the Centre for Comparative and Public Law, Faculty of Law, University of Hong Kong, the Hong Kong Equal Opportunities Commission, and the United Nations Division for Social Policy and Development, Hong Kong. She was also the Principal Coordinator in Canada for the National Resource Centre for Inclusion (India) Project in Bombay, India; Policy Advisor for Inclusion International in Geneva, Switzerland; and Consultant for the Government of Victoria, Australia, Ten Year State Plan for Disability.

She was frequently collaborating with Bengt Lindqvist – a Swedish politician and strong advocate of persons with disabilities. She was a member of the Social Democratic Party and served as chairman of the Swedish Association of the Visually Impaired from 1975 to 1985, the rehabilitation committee of the World Council for the Welfare of the Blind from 1974 to 1985, and the Swedish Disability Association from 1977 to 1985. First elected as a Member of the Riksdag (MP) for Stockholm County in 1982, Lindqvist also served as a deputy minister for social security (responsible for family affairs, elderly care and disability) in the Palme II and Carlsson I Cabinet and was later named minister without portfolio in the Carlsson II Cabinet. He moved to the UN where from 1994 to 2002, he served as the United Nations Special Rapporteur on Disability of the Commission for Social Development. They had a special relationship and often met in Sweden and New York to reflect on the status of human rights among persons with disabilities conceiving an international holistic monitoring project on the rights of persons with disabilities and the creation of a disability studies programs around the world.

In 2000, Marcia worked with Bengt as Policy Advisor to the UN Special Rapporteur for an International Expert Meeting on human rights abuses, "Let the World Know," in Stockholm, Sweden. At this Expert Meeting, Bengt brought together 27 experts from all regions of the world to consider measures to strengthen the protection and monitoring of the human rights of people with disabilities. Among the seminar participants were representatives of all the major international disability organizations, representatives of the Office of the High Commissioner for Human Rights and the UN Secretariat, disability rights activists, and experts on human rights. The participants recommended the creation of an international system to monitor the human rights situation of people with disabilities. To fill this need, Disability Rights Promotion International (DRPI) was founded by Marcia and Bengt.

Establishing Critical Disability Studies and International Rights Monitoring

In 2001, Marcia left Roeher and joined York University in Toronto, Canada, as a Full Professor. Originally appointed to Atkinson College, she accepted this position on the condition that she could establish both a School of Health Policy and Management (SHPM) and a Program of Critical Disability Studies (CDS) at the university. The goal was to develop a cadre of people skilled and knowledgeable about disability from a critical perspective. The university administration agreed to establish the program in the Faculty of Health (despite Marcia's objections to such a faculty home given the challenges and harms caused by the medical model of disability). The CDS program was created with input and consultation with leading disability studies scholars and activists around the world including Michael Oliver, Colin Barnes, Bengt Lindqvist, Nora Groce, as well as colleagues at the York Centre for Vision Research, among others. Saul Joel, Susan Warwick, and Rob Webb at York played a critical role in getting the program accepted through the university and provincial administration.

The program was designed with three areas of concentration: (1) human rights and social justice, (2) social policy, and (3) critical theory. These three areas of concentration were intended to be complementary and comprehensive. Students received education and courses in all three areas and could focus on one area or more in their research programs.

Simultaneously and complementarily, Marcia began to bring external governmental and international projects and grants such as DRPI into the Financial Services Department of York University as part of her development plan for SHPM and CDS.

At the rock bottom level, Marcia had to fight to make the classes accessible for students and faculty with disabilities. This was an ongoing battle with facilities that was later taken up by other program faculty. Only one classroom on campus was made fully accessible. Accessibility was considered regarding the built environment, information and communications, and student and faculty services. Marcia saw this as an integral part of the educational structure of the program. She emphasized the right to accessibility as a means to inclusion. As part of making Disability Studies important at York, she helped organize an Honorary Doctorate for Bengt Lindquist which made national and international news.

She developed a model at York for what she thought a Critical Disability Program or Department should be. Rather than try to make it exclusive to York, she systematically lectured at universities on all the continents and advised their disability scholars, organizations, on how to create a Critical Disability Department and if not a critical one at least a Department of Disability Studies. It is and will be a long-term continuing legacy.

As the convention on the rights of persons with disabilities (CRPD) was being created in the early 2000s, Marcia saw this as a tremendous opportunity to identify, address, and remove the challenges and barriers facing people with disabilities. The CRPD solidified the rights of persons with disabilities in an international treaty. Marcia was among the first in the world to develop educational and research activities to promote and monitor the implementation of the CRPD. She worked closely with her colleagues at York University, across Canada, and internationally. She worked closely with the Canadian government and in particular with members of the "blue jean bureaucracy." She also had many connections in national politics. She was a friend of Carolyn Bennett who was a Member of Parliament for St. Paul's and Minister for Public Health (and set up the governments Public Health Agency and Public Health Network), and William Young, biographer of Paul Martin and Brian Mulrooney, and the parliamentary librarian where his portfolio included being deputy head of the government responsible for parliamentary administration as well as research, information, public outreach, and education.

Just prior to the adoption of the CRPD in 2006, Marcia published her reflections on equality and well-being – picking up on the work she started with her Ph.D. dissertation and continued to develop throughout the 1990s. These reflections were published in a journal article in 1994 (Rioux, 1994b) and reprinted as a book chapter in 2005 titled: "Towards a Concept of Equality of Well-Being: Overcoming the Social and Legal Construction of Inequality." She wrote:

> The ways in which a society provides for people who, for one reason or another, are more socially and economically dependent throws into sharp focus the problems of equality as a political construct. The basic dilemma of social dependency is that of reconciling the responsibility of the state to ensure equality with the rights and needs of those who are dependent. . . (p. 127)
>
> Traditional limits that have circumscribed political obligation to ensure equality become suspect when the meaning of equality incorporates the notion of well-being, with its implications for resource distribution. Entitlement is based on a comprehensive notion of citizenship (that is, the intrinsic worth of the individual and on some absolute notion of need) not on ones status as a member of the class of worthy poor, or on inequality of talent or social usefulness. (p. 144)

Conversely, she believed that discrimination was:

> . . . tied to traditional notions of worth, (and) merely changing conventional definitions of discrimination may not by itself result in substantive equality. Structural changes are likely to be necessary on the political and legal levels. If the right to participate is to be recognized, the notion would have to be jettisoned that people with intellectual disabilities are members of a class provided with goods and services because they are worthy of care rather than by right of citizenship. (p. 144)

Finally, she argued for an outcome-based equality of well-being that

> . . .starts not with an assimilationist view but with a pluralist perspective on how people with differences and similarities ought to see each other in a just society. It argues that formal barriers have placed groups in substantively different social positions, i.e., that differences have become sites of social disadvantage. Consequently, removing the barriers without also redressing associated disadvantage does not result in significant change. This model also assumes that systemic discrimination against groups is not a "mistake" but an integral part of policies fostering a dominant social agenda. As such, it provides an alternative context for examining legal and social equality. To enable equality that takes into account immutable differences, differences must be accommodated in order to neutralize their effect as barriers to personal achievement and to entitlement as fully participating members of society, that is, barriers to personhood dignity and self-determination. The emphasis is then on the means of reasonable accommodation, rather than affirmative action. (p. 144)
>
> The premises of this model of equality are that all persons of distinguishable groups have the same needs for equality; that the capacity to exercise a right is not a distinguishing characteristic for the purpose of recognizing or denying that right; and that equality is consequent on the equal value, benefit, and rights possessed in differences from the norm, not on overcoming natural characteristics and becoming as much like the norm as possible.
>
> To achieve this form of equality would require the redistribution of state resources to actualize equality of well-being. Inequality would no longer be embodied in the concept of intellectual disability nor would intellectual disability be the basis for denying citizenship. The granting of entitlements could be attached purely by reason of an individual's being, independent of their potential to compete. This would refocus the concept of equality, both legally and socially, from the negative notion of "discrimination," to a positive means of integration. Distributive justice based on this idea of equality would require that social transfers were made not just in financial terms but in the basis of other needs as well, including support to participate.
>
> Setting the equality standard as an outcome measure removes the need for each disadvantaged group to demonstrate discrimination. It replaces the capacity to compete as the basis for political obligation. It takes into account the social reality of the disabled and non-disabled as well as their biological differences. And it thus makes the achievement of

> social justice dependent on a recognition of those differences that must be accommodated to achieve equality of well-being. (p. 147)

After the adoption of the CRPD, Marcia delivered a keynote address titled: “Promises and Panaceas: The Idealism of Rights to the Exercise of Rights” to the World Congress of Rehabilitation International, in Québec City, August 2008 (Rioux, 2008). In this address, she presented examples and experience of monitoring rights from a holistic perspective, including media monitoring, systemic monitoring (of programs, policies, and laws) and monitoring of individual situations. The presentation used examples from research that DRPI had already carried out in the field since 2002, to underscore the limitations of monitoring that doesn’t measure the gap between government policies, programs, and constitutional guarantees and the reality for people with disabilities who continue to live without their rights. In this address, she said:

> After more than 30 years of lobbying and advocacy we have finally reached the plateau where human rights and disability have become firmly linked. With the first statements of Mary Robinson acknowledging that disability was a human rights issue (in the late 1990s) to the newly signed United Nations Convention on Disability, this connection has become entrenched in the UN rhetoric. It is also now found in national state rhetoric where governments are signing and ratifying the Convention.

This recognition of disability rights is a watershed but not by any means a panacea. The next steps are more difficult. How do we engage in enabling the exercise of those rights? Implementation in practice depends on some very important elements. These are:

1. The Convention itself and the way it is structured.
2. An on-going dialogue and buy-in by the public of disability rights as shared social values.
3. Building an awareness of disability rights values in government and the legal system across all sectors in each country.
4. Requirement of public authorities to take account of civil, political, economic, social, and cultural rights in policy making.
5. Putting in place a National Disability Strategy supporting rights that incorporates. . .principles of indivisibiltiy of rights and responsibilities. . .a rights assessment tool, logic mapping for prioritizing strategy, and careful and detailed monitoring of the strategy against the principles of the UN Convention.
6. Finally and of critical importance had to be real, sustainable and on-going holistic monitoring of the Convention and of other UN instruments that guarantee rights.

Marcia strongly spoke about how the importance of having these six elements cannot be exaggerated.

During this period of her life, she might work at York for a week, go to Ottawa for a few days, and then fly to London with Carolyn Bennett. There she would meet with Mithu Alur representing Indian Disability Societies and then go with Carolyn Bennett to the English House of Commons in order to have committee meetings on upcoming

UK disability legislation and the next day visit with Oliver and then Barnes about setting up a CDS program. There were visits with Nora Groce and staying at her place on Hampstead Heath. For anyone, it would have been a grueling schedule.

She had considerable outreach and was often interviewed on human rights, disability, women's rights, and social justice by the media. You would find her on CBC including discussions with CBC Morningside with Peter Gzowski, and subsequently Shelagh Rogers and Stuart McLean. There were similar interviews in the United Kingdom, France, Italy, Germany, and by Asian and African newspapers. All of this work was in one way or another linked to the promotion of disability rights internationally.

Disability Rights Promotion International (DRPI)

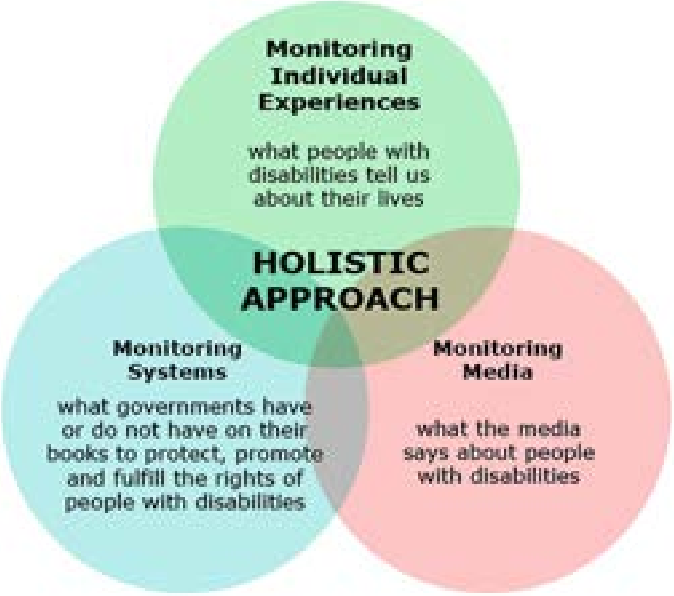
The first phase of DRPI was launched in 2002 with a research agenda that investigated opportunities for using international human rights instruments to enforce disability rights; types of monitoring tools used by human rights monitoring projects; and current training resources for human rights monitors and for more general human rights education. This research confirmed the need for increased disability rights monitoring activities and for disability-specific monitoring and training resources; identified existing expertise, models, and methodologies related to human rights monitoring in the five areas of focus; and highlighted opportunities for disability rights advocacy in the international human rights system.

In addition to research, the DRPI team reached out to many organizations to identify partnership opportunities. This exploration of partnerships continued as plans were developed to implement a monitoring system. One goal was to form effective working relationships with human rights and disability organizations to share expertise and develop field testing sites for monitoring (Disability Rights Promotion International, n.d.-a).

Seven years later, the DRPI initiative was officially implemented. By 2012, instruments and tools were being used in more than 20 countries, to foster permanence and sustainability of monitoring the implementation of the CRPD. The initiative was sustained through the establishment of continental regional centers in collaboration with organizations operated by and for persons with disabilities. These centers were regional focal points for disability rights monitoring activities. They worked together to create a sustainable and coherent structure that would continue over many years. DRPI reported to the UN Special Rapporteur and strengthened the international network of persons with disabilities and disability organizations to enhance their capacity with skills to manage, coordinate, and participate in disability rights monitoring projects. Existing collaborations continued and new partnerships were explored. By 2013, "a strong foundation was put in place for a comprehensive and sustainable global disability rights monitoring system, involving the networks and organizations of persons with disabilities needed to support the work" (Disability Rights Promotion International, n.d.-a).

The DRPI initiative has adopted three broad areas for monitoring: monitoring systems, monitoring individual experiences, and monitoring media. Human rights monitoring has been broken down into these areas to discover discrete pieces of knowledge and create a picture of the current situation faced by individuals with disabilities. Data collected during monitoring activities in all three areas are used as evidence for advocacy efforts and the improvement of government policies and laws.

The three broad areas for monitoring, monitoring systems, monitoring individual experiences, and monitoring media, are represented in the following Venn diagram.



The DRPI monitoring system is a powerful and empowering project because "it provides a voice to marginalized people, enhances public awareness by documenting abuses and violations reinforces a collective identity among persons with disabilities, and supports efforts to achieve social justice" (Disability Rights Promotion International, n.d.-b). DRPI remains active today. The knowledge and reports produced as well as the rights monitoring training are freely available online and accessible (Visit: https://drpi.research.yorku.ca/ and https://drpitraining.research.yorku.ca/drpihub/

Impacts and Achievements: An Illustrious Career

Marcia's collaborative work has had tremendous social and geographic reach and impact. Marcia supervised 85 students across various programs including critical disability studies, law, history, political science, education, computer science, and humanities. Since the beginning of DRPI, over 50 monitoring projects have been developed including people with disabilities from 49 different countries who participated in DRPI training. In addition, at least 24 universities across the world (e.g., India, South Africa, Germany, Portugal, Kenya, United States, Sweden, etc.) have collaborated with DRPI.

The accessibility of DRPI is a reflection of Marcia's drive and commitment to making knowledge accessible to everyone. She engaged in academic and public pedagogy with a strong focus on impact by enhancing the capacity of people with disabilities to advocate for their rights. An example of this effort is articulated in The People's Indicators: Evidence Based Participatory Indicators – Measuring Progressive Realization (Rioux, 2017) which provided an adequate and sufficient basis for groups around the world to determine their relative status regarding on the ground behavior by governmental and religious bodies. She was adamant about all projects being participatory.

The People's Indicators were drawn from over a decade of work under the DRPI initiative. The indicators were derived from hundreds of individual and group interviews with persons with disabilities around the world who spoke and communicated about their rights within the context of monitoring the implementation of the CRPD.

From 2017 onward, the work of DRPI evolved into article/issue-specific areas such as employment (Rioux et al., 2019) with an explicit focus on gender and women with disabilities, and indigenous issues (Gillespie et al., 2016). The emphasis here was to increase awareness of the human rights experiences of diverse people with disabilities.

As the second decade of the twenty-first century ended, Marcia's interest turned to disability and indigenous communities. She always had an interest, and she frequently interacted with indigenous groups in the various countries in which she worked. This included indigenous European groups such as the Sami and Roma, African tribal groups, Middle Eastern Beduions, and a variety of groups from India and Granada. However, she began to focus on the Cree, Mohawks, Inuit, and Athapaskan groups as well as the Northwestern tribes. She started to lecture at many of their conferences and to tribal organizations.

Before her retirement, Marcia created an endowment of knowledge and legacy of open-access resources (e.g., DRPI online training, reports, data collection tools), books, and an established credible disability studies program and community-based education resource for people with disabilities around the world. We have listed many of these publications and resources below. It is an extensive and broad list.

Sometimes, the monitoring reports from DRPI and Marcia's many other publications, teaching, and presentations were listened to by governments, and policy changed, and sometimes not. One of Marcia's greatest achievements was her cocreative efforts that resulted in people with disabilities in numerous countries becoming aware of their rights and how their rights should be guaranteed by their governments, as well as the discontinuity between what should be and what was. This knowledge created action. People with disabilities were empowered to advocate for their rights. They began to see themselves as equal citizens with rights and freedoms, responsibilities and entitlements, and as autonomous dignified individuals connected to a global community of people with shared lived experiences. Marcia was brave, and she was willing to be very uncomfortable in order to do what was necessary to move knowledge to action.

Over the course of her career, Marcia received 17 honors and awards for her contributions to scholarship, research, practice, and advocacy. These honors and awards ranged from early career scholarships and fellowships, visiting professorships and distinguished fellowships, professional recognition awards and all the way up to the receipt of a Queen Elizabeth II Diamond Jubilee Medal, Governor General of Canada as well as the Order of Canada. However, she would say that her greatest reward was the look in people's eyes when they realized that they had rights that could not be taken away.

Lifetime Summary of Publications

Books and Monographs

2017 DRPI People's Indicators: A Participatory, Holistic and Community Based Monitoring System (M.H. Rioux, Principle Author and Editor, J. Viera, P. Pinto, Rados, Keravica, D. Wakene, R. Rathuri, P. Hearne). On-line publication.

2015 Disability, Rights Monitoring and Social Change: Building Power out of Evidence (Eds. M.H. Rioux, P.Pinto, G. Parekh) Toronto, Canada: Canadian Scholars Press.

2011 Critical Perspectives on Human Rights and Disability Law, (Eds. M. H. Rioux, L. Basser, M. Jones). The Hague: Martinus Nijhoff.

2010 Staying Alive: Critical Perspectives on Health, Illness and Health Care, 2nd Edition. (Eds. T. Bryant, D. Raphael, M. H. Rioux). Toronto: Canadian Scholars' Press Inc.

2009 Landscape of Literacy and Disability, (Eds. E. Zubrow, M. H. Rioux, M. Dinca-Panaitescu, C. Spielman, A. Marsolais). Toronto, Canadian Abilities Foundation.

2006 Staying Alive: Critical Perspectives on Health, Illness and Health Care, (Eds. D. Raphael, T. Bryant, M. H. Rioux). Toronto: Canadian Scholars' Press Inc.

2003 Atlas of Literacy and Disability, (M. H. Rioux. E. Zubrow, M. Stutt Bunch, and W. Miller). Toronto: Canadian Abilities Foundation.

2002–2009 Book series. Inclusive Education: Cross Cultural Perspectives, (Eds. L. Barton, M. H. Rioux). The Netherlands: Kluwer Academic Publishers. (5 books published).

1996 Reflections on the Canada Health and Social Transfer, (An Occasional Paper) (Eds. M. H. Rioux, M. Bach). North York: The Roeher Institute.

1994 Disability is not Measles: New Research Paradigms in Disability, (Eds. M. H. Rioux, M. Bach). Toronto: The Roeher Institute.

1994 Canadian Disability Resource Program. (Eds. M. H. Rioux, C. Crawford) North York: The Roeher Institute.

Chapters in Books

2019 Rioux, M, Pinto, P. Wakene, D. “Reinventing Activism: Evidence-based participatory monitoring as a tool for social change” Berghs, M., Chataika, T., El-Lahib, Y. & Dub, A.K. (Eds.) 2019. The Routledge Handbook of Disability Activism. London and New York: Routledge.

2017 “International Human Rights and Intellectual Disability” (Pinto, P., Rioux, M.H., Lindqvist, B. & Carbert, A.) In I. Brown and M. Percy A Comprehensive Guide to Intellectual and Developmental Disabilities (2nd Edition): Brookes Publishing Company.

2016 “Disability Research in the context of the Global South: Building Southern Sustainability through an Emancipatory, Evidence-based and Locally Initiated Approach” (Rioux, M.H., Pinto, P., Viera, J., and Keravica, R). In S. Grech and K. Soldatic (Eds.), Disability in the Global South: The Critical Handbook. US: Springer.

2015 “Employment, Poverty, Disability and Gender: A Rights Approach for Women with Disabilities in India, Nepal and Bangladesh” (Buettgen, A., Gorman, R., Rioux, M., Das, K., Vinayan, S.) In Khanlou N & Pilkington B. (Eds). Women’s Mental Health: Resistance and Resilience in Community and Society, Advances in Mental Health and Addiction (Series Editor: Masood Zangeneh). New York: Springer.

2014 “Employment Equity and Disability: Moving Forward to Achieve Employment Integration and Fulfill Promises of Inclusion and Participation” (Rioux, M.) In M. S. Lynk, J. Craig, C. Agocs (eds) Employment Equity in Canada. Toronto: University of Toronto Press.

2014 “Human Rights in Context: Making Rights Count” (Rioux, M. & Bonita Heath) in Swain, J., French, S., Barnes, C. And Thomas, C. (eds.) (2014) Disabling Barriers; Enabling Environments (3rd edition), London: Sage.

2014 “Disability Rights In Education” (Rioux, M.) In L. Florian (ed), Sage Handbook of Special Education (2nd Edition), England: Sage Books.

2014. Rioux, M. & Pinto, P. (2014). Are We Moving Forward? Regional Study on the Rights of Women with Disabilities in the Middle East. Disability Rights Promotion International. Available online: http://drpi.research.yorku.ca/middle-east-north-africa/middle-east-north-africa-publications-resources/2014-women-with-disabilities-in-the-middle-east-regional-study/

2013 “Negotiating Capacity: Legally Constructed Entitlement and Protection” (Rioux, M., Gilmour, J. and Angel-Cabo, N.) in B. McSherry, I. Freckelton, (eds) Coercive Care: Rights Law and Policy, Abingdon, Oxon: Routledge, 51–75.

2011 “The Rights of People with Intellectual Disabilities in Ontario” (Rioux, M.H., Frazee, C., Patton, L.M.) In I. Brown & M. Percy, Developmental Disabilities in Ontario (3rd Edition), Ontario Association on Development Disabilities, 65–74.

2011 “Values in Disability Policy and Law: Equality.” In M. H. Rioux, L.A. Basser, M. Jones (eds), Critical Perspectives on Human Rights and Disability Law, The Hague: Martinus Nijhoff, 36–56.

2011 “Beyond Legal Smokescreens: Applying a Human Rights Analysis to Sterilization Jurisprudence.” In M. H. Rioux, L.A. Basser, M. Jones (eds), Critical Perspectives on Human Rights and Disability Law. (with L. Patton) The Hague: Martinus Nijhoff, 243–272.

2010 “Rights on the Ground: Disability Rights in the Time of the United Nations Convention on the Rights of Persons with Disabilities” (M. H. Rioux) In Le Tribunal des droits de la personne et le Barreau du Quebec. Race, Femme, Enfant, Handicap: les conventionsinternationales et le droit interne a la lumière des enjeux pratiques du droit a l’égalité. Quebec, Quebec Editions Yvon Blais, p. 107–138.

2010 “Constructing Disability and Illness” (M. H. Rioux, T. Daly). In Staying Alive: Critical Perspectives on Health, Illness and Health Care, 2nd edition. Toronto: Canadian Scholars’ Press Inc. 347–370.

2010 “Researching Health: Knowledge Paradigms, Methodologies, and Methods” (T. Bryant, D. Raphael, M. H. Rioux) In Staying Alive: Critical Perspectives on Health, Illness and Health Care.2nd edition Toronto: Canadian Scholars’ Press Inc. 121–143.

2010 “The Right to Health: Human Rights Approaches to Health.” (M. H. Rioux) In Staying Alive: Critical Perspectives on Health, Illness and Health Care.2nd edition Toronto: Canadian Scholars’ Press Inc. 93–121.

2009 “Inclusive education in Atlantic Canada: the research in context.” (M. H. Rioux, K. Underwood). In G. Bunch & A. Valeo, (Eds.). Inclusive Education: Emergent Solutions. Toronto, ON: Inclusion Press, 100–117.

2009 “Early Intervention and Inclusive Education”, (M. Alur, M. H. Rioux). In M. Alur & V. Timmons, Inclusive Education Across Cultures: Crossing Boundaries, Sharing Ideas, England: Sage Books. 137–160.

2006 “Disability Rights in Education” In L. Florian, Handbook of Special Education, England: Sage Books. 107–116.

2006 “International Human Rights and Intellectual Disability” (M. H. Rioux, B. Lindqvist & A. Carbert). In I. Brown & M. Percy, Intellectual and Developmental Disabilities: International Edition. Baltimore, USA. 59–68.

2006 “Trends in Disability” (M. H. Rioux, R. Samson). In M. A. McColl & L. Jongbloed, Disability and Social Policy in Canada (2nd edition), Captus Press. pp. 112–142.

2005 “Towards a Concept of Equality of Well-Being: Overcoming the Social and Legal Construction of Inequality.” (M.H. Rioux) In P. Blanck, Disability Rights. Great Britain: Ashgate Press. 467–487 [reprint].

2005 “Does Theory Matter? Exploring the Nexus between Disability, Human Rights and Public Policy” (M. H. Rioux, F. Valentine). In D. Pothier & R. Devlin, Critical Disability Theory: Legal and Policy Dimensions, Vancouver: UBC Press, 47–69.

2003 “On Second Thought: Constructing Knowledge, Law, Disability and Inequality” (M.H. Rioux) In S. Herr, L. Gostin and H. Koh, The Human Rights of Persons with Intellectual Disabilities: Different But Equal. Oxford University Press. 287–317.

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New Politics of Disablement

The Contribution of Mike Oliver

3

Ravi Malhotra

Contents

Abstract

Michael Oliver (3 February 1945 to 2 March 2019) was a British academic, author, and disability rights activist. He was Emeritus Professor of Disability Studies at the University of Greenwich. His research focused on the social model of disability, and his activism centered on overcoming the systemic barriers disabled people confront in their daily lives. We present below a memoir of his contribution to building disability studies and a movement demanding inclusion and equality for disabled people.

Introduction

Mike Oliver, Emeritus Professor of Disability Studies at the University of Greenwich in England, has died at the age of 74 after a short illness. A long-time wheelchair user since the age of 17, a sociologist by training and author of many books including his

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landmark texts, *Social Work with Disabled People* (1983) and the *Politics of Disablement* (1990) and (with Colin Barnes) *The New Politics of Disablement* (2012). Oliver played a pioneering role in developing, with others such as Vic Finkelstein, what has come to be known as the social model of disability. The model builds from the proposition that it is structural barriers, such as a lack of wheelchair ramps or a failure to provide sign language interpreters, which impede disabled people rather than the impairments themselves. In other words, systemic barriers constitute an ableist society that immobilizes disabled people and keeps them largely unemployed and in poverty. In every advanced capitalist country, disabled people face tremendous barriers in housing, transportation, and employment. These barriers are so widespread and comprehensive that most individuals do not give them a second thought.

The Social Model of Disablement

By establishing and popularizing what has become known as the impairment-disability distinction, Oliver convinced disabled people to view the discrimination that they face daily as a matter of rights rather than a personal tragedy or medical problem. In other words, the fact that Jill has broken her leg means that she has an impairment, but she cannot get to class because the school does not have a functioning elevator. The inaccessible school is a disabling barrier that has to be remedied. It is difficult to convey how revolutionary the social model of disability was in crystallizing the consciousness of disabled people. Individuals who had spent years regarding their daily difficulties as a matter of personal failure and were socialized by an array of physiotherapists, occupational therapists, and physicians to focus on rehabilitation were suddenly politicized as they came to realize that disability was indeed a political issue. Sometimes this has been misinterpreted as an attack on the medical profession. However, Oliver is very clear that the social model is not anti-medicine where medical intervention is required. Rather he is against "medical imperialism," a mode of thought that regards disabled people as irremediably broken.

Activists chose to prioritize different strategies. Many disabled people, more influenced by postmodern theories of language and the body, have tended to focus on cultural studies and the representation of disabled people in cinema, dance, and sports. Others have chosen to engage in law reform strategies such as advocacy for human rights legislation and test case litigation, with all its promise and perils, to seek social transformation. Still others have focused more directly on grassroots mobilization to challenge the austerity agenda of neoliberal governments – an anti-capitalist route. Certainly, all have merits and, indeed, some have chosen to combine them, but it is the last road that most closely corresponds to Oliver's prescient vision of transforming the lives of disabled people for a better future.

Class Politics and Institutionalization

Oliver was deeply influenced by class politics and laid the basis for the still unfinished product of a materialist theory of disablement. He very much believed that the rise of capitalism and the factory system created disability. The requirements of wage labor as the dominant mode of production entailed the segregation and exclusion of disabled workers who could not maintain efficient production standards in an industrial society. As many scholars have noted, the very notion of time functioned differently in agrarian rural societies. Those who failed to conform and work at a pace set by Fordist factories were consigned to “workhouses, asylums, impairment-specific colonies and special schools and out of the mainstream of economic and social life” (Oliver and Barnes, 2012, p. 55). Social Darwinism and eugenics provided an ideological justification for the exclusion of those individuals who could not conform to the requirements of industrial capitalism.

As many scholars of “mad studies” have noted, the actual impairments were often irrelevant. People incarcerated in psychiatric institutions notoriously did not necessarily have a formal diagnosis. As Geoffrey Reaume has shown in his book, *Remembrance of Patients Past* (2000), some were simply housewives who refused to conform to gender norms or even individuals who were misdiagnosed because they had acted in an unusual manner and spoke foreign languages that authorities could not understand. By associating ability with productivity, the workhouses and asylums served as a warning to the able-bodied population and stigmatized those who fall outside the boundaries of normality. Theories of eugenics of course entailed both stigmatization of disability and racial classifications that sought to exclude immigrants who were a danger to society. At its nadir, this culminated in the eugenics policies of Nazi Germany where hundreds of thousands of disabled people were exterminated in accordance with instructions from Hitler in 1939, but it is often forgotten that early twentieth-century social democratic politicians around the world were enthusiasts of eugenics measures.

In the twentieth century, Oliver showed how the state engaged in a neoliberal “decarceration strategy” that saw the closure of many institutional settings in Western countries. However, this was done in the context of inadequate services that did not allow disabled people to flourish. What remains to this day are massive and inflexible bureaucratic requirements for eligibility for social assistance. It is not uncommon for individuals to entail significant difficulty and repeated rejection in navigating a process that is designed to exclude as many people as possible.

The Role of Professionals

Oliver also played an important role in identifying the role of professionals who work with disabled people and build a career providing services that do little to empower them. He was particularly pointed in criticizing middle-class professionals whom he felt exploited disabled people, created a culture of dependency, and systematically ignored their life experience, hence the slogan of the disability rights movement: “nothing about us without us.” He also developed interesting insights on the need for disabled people to acquire a consciousness around disability politics. Unusually for an academic, he combined grassroots activism with his scholarly work and was influenced by the work of militant disability organizations such as the Union of the Physically Impaired Against Segregation (UPIAS), which was founded in 1974. Their 1976 manifesto, *Fundamental Principles of Disability*, articulated many of the distinctions between impairment and disability that Oliver would go on to develop. He fittingly became the first professor of disability studies in Britain.

Disability Rights Activism and the Left

His powerful ideas have influenced an entire generation of disabled people, particularly in the Commonwealth countries, despite the fact that the socialist Left has all too frequently ignored disability rights activism. I was privileged to hear him speak around 1994 at Carleton University in Ottawa in which he spoke about disability rights and referenced Gramsci. This is hardly surprising as Oliver has written eloquently on the ideological construct of individualism. In the disability context, this is manifested through medicalization, the requirements of normality and eugenics (Oliver and Barnes, 2012 p. 79). While many have since questioned whether the social model adequately integrated identities such as race and gender and whether it adequately encapsulates the experience of those with chronic conditions that involve significant physical pain, the debates still relate back to Oliver’s pioneering work. There is no doubt that there were elements of pessimism in his later work. Oliver thought that the transformation of capitalism was not on the immediate agenda in the face of widespread neoliberal cuts.

That understandable pessimism does not diminish the immense value of his transformative model and his legacy. All the writing I have done since then, including my anthology in honor of the late American disability rights advocate Marta Russell, *Disability Politics in a Global Economy* (2016), and other topics, are predicated on the epistemic foundation established by Oliver. Marta Russell’s landmark book, *Beyond Ramps* (1998), has undoubtedly been better received in Britain and other countries than in Canada and the United States in part because Oliver’s materialist conception of disablement has wider currency. At the same time, few scholars have developed a full-fledged historical materialist theory of disablement as postmodernism dominates current disability studies departments, despite significant contributions by Marta Russell, Sunny Taylor (2004), Jim Charlton (1998), and others.

Today disability rights advocates continue to play an important role in challenging austerity including vigorous protests in the American Congress against Republican attempts to repeal the *Affordable Health Care Act*. In 2019, the Canadian Parliament passed the very limited and largely toothless *Accessible Canada Act* (see the critique of the Council of Canadians with Disabilities), some 30 years after the passage of the more robust *Americans with Disabilities Act* in the United States. Disability rights advocates around the world owe an enormous debt of gratitude to Mike Oliver.

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Bengt Lindqvist: A Prominent Figure and Advocate

4

Alexis Buettgen and Ezra Zubrow

Contents

Abstract

This chapter presents highlights of the career and perspectives of Bengt Lindqvist – a prominent voice for disability rights internationally. Bengt Olof Lennart Lindqvist was born in Helsingborg Sweden on June 3, 1936, and died on December 3, 2016. Bengt was a dedicated career politician. He was an expert at using the leverages of political power to help people with disabilities. A lifelong member of the Social Democratic Party, he was first elected as a Member of the Swedish Parliament representing Stockholm County from 1982 and continued to serve for 12 years to 1995. From 1994 to 2002, Bengt Lindqvist served as the United Nations Special Rapporteur on Disability of the Commission for Social Development. In addition, he served as chairman of the Swedish Association of

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the Visually Impaired from 1975 to 1985, the rehabilitation committee of the World Council for the Welfare of the Blind from 1974 to 1985, and the Swedish Disability Association from 1977 to 1985. Together with Marcia Rioux, he created Disability Rights Promotion International and was its codirector until his death. During his lifetime, he received a wide variety of awards including honorary doctorates. He traveled the world and the seven seas looking for everything to use, looking for something, to keep moving on, and advance the rights of people with disabilities.

Short Biography and Introduction to Bengt

Bengt Olof Lennart Lindqvist was born in Helsingborg Sweden on June 3, 1936, and died on December 3, 2016. For most of his life, he was completely blind. He was a long-term personal friend of Marcia Rioux, and together, they developed many of the ideas that became central to the Human Rights and justice paradigm – including the development of Disability Rights Promotion International (DRPI). Unlike Marcia, Bengt was a dedicated career politician. He was an expert at using the leverages of political power to help people with disabilities. A lifelong member of the Social Democratic Party, he was first elected as a Member of the Swedish Parliament representing Stockholm County from 1982 and continued to serve for 12 years to 1995. He held important political and administrative positions in the Swedish government serving as a deputy minister for social security (responsible for family affairs, elderly care, and disability) in the Palme II and Carlsson I Cabinet and was later named minister without portfolio with the same responsibilities in the Carlsson II Cabinet.[1]

From 1994 to 2002, Bengt Lindqvist served as the United Nations Special Rapporteur on Disability of the Commission for Social Development. In addition, he served as chairman of the Swedish Association of the Visually Impaired from 1975 to 1985, the rehabilitation committee of the World Council for the Welfare of the Blind from 1974 to 1985, and the Swedish Disability Association from 1977 to 1985. Together with Marcia Rioux, he created Disability Rights Promotion International and was its codirector until his death During his lifetime, he received a wide variety of awards including honorary doctorates. He traveled the world and the seven seas looking for everything to use, looking for something, to keep moving on, and advance the rights of people with disabilities.

This chapter begins with Marcia Rioux's remembrance of Bengt posted on the DRPI site shortly after his death. Next is a welcome message Bengt shared in 2011 with the community of DRPI participants who took part in both the online and in-person trainings. The chapter concludes with excerpts from one of Bengt's last writings – a 2015 book chapter on disability rights monitoring and social change. These excerpts capture his key reflections on how to progressively realize human rights for all.

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[1] See also: https://en.wikipedia.org/wiki/Bengt_Lindqvist

Marcia Rioux's Remembrance of Bengt

Bengt had a singular influence on disability of the 20th and well into the 21st century. His contribution is profound. Not because he had a disability but because he understood social justice in a way that he was able to put it in practice in all the many different lives he had – as a teacher, as a politician, an as an advocate, as a UN Special Rapporteur on Disability, as a father, as a husband, and as a jazz musician. He recognized so clearly and unfailingly that the voices of people with disabilities were the voices we needed to hear and what was said by those voices had to be the only agenda in addressing the denial of rights, and exclusion. He never bent in his resolve to make those voices heard.

His influence is legendary and recognized by both the famous and the average person who he met on his journey. He had an impact on every person he met.

By profession, Mr. Lindqvist trained and practiced as a language teacher. His interest in equality and disability led him to advocate and work on issues of disability policy in the 1960s. In 1982, his passions for politics led to him becoming a Member in Parliament in Sweden, serving as the Minister of Social Service and Family Affairs between 1985 and 1991. Between 1994 and 2003 Mr. Lindqvist served as the United Nations Special Rapporteur on Disability, where he led the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, the framework that promoted participation and equality for people with disabilities. Before anyone was thinking of monitoring and the CRPD was not even yet on the political agenda, Bengt held a conference in Almosa, Sweden, in which the 28 participants, including representatives of all the international disability organizations as well as the UN, heralded jurists and others detailed a way to monitor the rights of persons with disabilities. It stands to this day as the model for participatory, holistic monitoring rights – through the voices of persons with disabilities. And the oak tree he planted at that meeting as a symbol for the work that was beginning still grows in the gardens of Almosa getting stronger and bigger each year. Bengt said it was the symbol of what we could achieve and it is. In partnership with me, he co-founded, after that meeting, Disability Rights Promotion International (DRPI), in 2003 in an effort to design a methodology for participatory disability rights monitoring internationally. Bengt has provided dedicated leadership as Co-Director of DRPI in the process of mapping the monitoring of the rights of people with disabilities internationally. His wisdom and knowledge and strength shine through that as they are found in all his struggles for justice

Bengt Lindqvist's achievements were recognized by many communities internationally, including receiving honorary doctorates from York University (2013), Stockholm University (1999), and Lund University (2002). (This message can also be found at: https://drpi.research.yorku.ca/remembering-bengt-lindqvist-co-director-of-drpi/)

Bengt's DRPI Welcome Message

Let me look back a little bit, you know I am an old man by now and I was involved in disability policy already in the late 1960s. A sociologist, Robert A. Scott, wrote a book with the title, The Making of Blind Men, where he showed how people with disabilities, like no other group in society, are in the hands of experts, of doctors, nurses, social workers, teachers and also by their family and relatives, and that though, the values that these people have, to a very large extent, form the lives of people with disabilities.

When awareness grew about this phenomenon, of course we ourselves said that we must catch more influence, we must build capacity to take our own destinies into our hands, and you can see in many of the international documents, a trend to emphasize more and more, the role of disabled people themselves in deciding on their own lives and what should be priorities, and what should be done in the disability field. You have it in the World

> Programme of Action, you have it in the Standard Rules, and you also have it in the new Convention, and in the Convention its quite unique that the influence of people with disabilities themselves is so clearly stipulated in the different provisions of this Convention, like no other UN convention actually.
>
> Well, so the voice of people with disabilities is the most important voice in creating initiatives and action to improve the living conditions of people with disabilities. When the breakthrough took place in the UN and the UN human rights establishment recognized finally that disability is human rights dimension which has to be taken into account by human rights organizations and by the UN human rights institutions, that was great event in the disability history of course and it also presented a real challenge. How are we going to catch all the different forms of exclusion and discrimination that disability creates throughout the world? Well, the best answer is ask the people with disabilities themselves. They can tell you, they know, and our intention has been all the time to develop two things. (Lindqvist DRPI Welcome Message: https://drpi.research.yorku.ca/drpi-resources/a-welcome-message-from-drpi-co-director-bengt-lindqvist/)

Excerpts from Bengt's Writings

Below are excerpts from a book chapter Bengt wrote in 2015 as a leader in the development of monitoring disability rights. The chapter encompasses some of his core ideas, values, and principles in how monitoring can promote the progressive realization of human rights for all.

The Development of Human Rights for People with Disabilities in the International Context

In 1976, the UN proclaimed 1981 as the International Year of Disabled Persons (IYDP) (UN, 1981). The proclamation generated mixed feelings within the disability community. While disability-related charity organizations saw an emerging opportunity for increased publicity and the potential for additional resources, people with disabilities themselves were less enthusiastic. Concerned that the IYDP would continue to envision disability within traditional conceptualizations, relegating people with disabilities to roles of needing care or as charity recipients, people with disabilities sought to establish new ideas about disability within the UN framework. Their position was supported by the UN's announcement that the theme of IYDP would be "full participation and equality" (UN, 1981).

By focusing on these concepts, the IYDP opened up a field where a new political approach could be applied to the understanding of disability. The old method of concentrating all efforts to improve the capacity of the disabled individual was simply not sufficient. A shift of focus took place. From then on, much more attention had to be directed toward the surrounding society and any shortcomings and obstacles that prevented participation by persons with disabilities. In this way, the issue of disability became a political issue, an issue of how to design and build a society for all.

For disabled persons' organizations (DPOs) in Scandinavian and some English-speaking countries, this was a natural extension of a movement to embrace a new conceptualization of disability, one that emphasized equality, participation, and independent living.

During the late 1970s, activist groups and individuals with disabilities undertook several initiatives to increase the influence of disabled people themselves in all matters concerning their lives. For example, steps were taken to merge the two competing international organizations for people who are blind, only one of which was controlled by blind people themselves.

The merger took place in 1984, when the World Blind Union was formed. The new organization "provided a forum where people who were blind or had low vision established the right to speak for themselves" and acknowledged that "the majority of national delegates must come from recognised movements of blind and low vision people themselves" (World Blind Union, n.d.).

Perhaps the most spectacular and the most politically important example of the changing role of people with disabilities within disability organizations took place in 1980. Rehabilitation International, a large and influential international disability organization, held its congress in Winnipeg, Manitoba, Canada. Several thousand participants were involved, most of them nondisabled people. In previous years, there had been discussion about the necessity of increasing the influence of persons with disabilities, bur at that point, little progress had been made toward that goal. At the 1980 Congress, the Swedish delegation proposed a constitutional change that would give national DPOs the majority in the national delegations of Rehabilitation International (Driedger, 1989). The proposal generated a long and even aggressive debate. Ultimately, the proposal was rejected, creating great frustration and anger among the DPO representatives (Driedger, 1989, p. 37). In a parallel action, the Coalition of Provincial Organizations of the Handicapped (COPOH, now the Council of Canadians with Disabilities, or CCD) had been preparing for a new initiative, a new international organization representing all types of disabilities. As a consequence, a number of organizations supporting the right of self-representation for persons with disabilities established a new cross-disability organization consisting exclusively of national DPOs. This new organization was Disabled Peoples' International (DPI), and it was formally established a year later in Singapore (1981). DPI adopted a political manifesto based on human rights and nondiscrimination (DPI, 2012). Many of its representatives became delegates to the UN Advisory Committee established to lead activities throughout the IYDP. These events are important to keep in mind when analyzing the outcome of the IYDP. Never before had representatives of DPOs played as prominent a role in the UN context as they did in all of the major decisions, both during the preparations for activities and in elaborating the final outcome of the IYDP.

In 1982, the General Assembly adopted a resolution known as the World Programme of Action Concerning Disabled Persons (hereafter the World Programme). The elements of the World Programme were to be implemented during the International Decade of Disabled Persons 1983–1992 (hereafter the International Decade) (UNEnable, n.d.-a).

The discussions of the Advisory Committee on the contents of the World Programme were very lively and constructive. Thanks to excellent chairmanship and a hard-working secretariat, a text was developed, which, for the first time in history, gave the world community a comprehensive and coherent policy concerning all aspects of disability matters. The overall goal was to give meaning and content to the IYDP's theme, which was "full participation and equality." One important contribution of the World Programme was the identification of three main areas for action: prevention, rehabilitation, and equalization of opportunities (UNEnable, 2006a, n.d.-b). The first two areas were already well known and established in disability rights communities, but the third area, that concerning equalization of opportunities, was innovative, bringing the shortcomings and barriers to participation in society into focus. In the World Programme, this area is defined as follows:

> Equalisation of Opportunities means the process through which the general system of society, such as the physical and cultural environment, housing and transportation, social and health services, education and work opportunities, cultural and social life, including sports and recreational facilities, are made accessible to all. (UNEnable, 2006a, para. 6)

During the sessions to establish the World Programme's Advisory Committee, the issue of disability and human rights was brought up several times. It was the Canadian delegation that took the lead in these discussions and presented draft texts in order to obtain recognition of the fact that disability is a human rights concern for the UN; however, the vast majority of delegations held the view that disability, first and foremost, is a social development issue and should be treated as such by the UN (UNEnable, 2006a, n.d.-b). With the support of a few other delegations, the Canadians finally succeeded in gaining approval to include a few paragraphs on the subject near the end of the document. This text later proved to be of great importance.

A Special Rapporteur on Disability and Human Rights Appointed

In 1984, based primarily on concerns arising from the World Programme, the UN Sub-Commission on Prevention of Discrimination and Protection of Minorities (currently the Sub-Commission on Prevention of Discrimination and Protection of Human Rights) appointed Leandro Despouy as Special Rapporteur to study and analyze the relationship between human rights and disability (Despouy, 1992). Despouy's final report, Human Rights and Disability, "chronicled wide-spread human rights abuses in the area of disability" (Rioux & Carbert, 2003, p. 3).

The Issue of a Special Convention About Disability

In the mid-1980s, many representatives of international disability organizations believed that the disability issue was losing momentum around the world. According to them, the World Programme was too vague in identifying the responsibility of governments and that more active monitoring from the UN was needed. In the International Decade's guidelines, a mid-term evaluation was required in 1987.

Collaborating with a few other delegations, the Swedes utilized the slightly different attitude among delegations in 1989 and suggested that a new type of policy document should be drafted. They found a model in the UN's recommendations concerning standards for conditions in prisons, a document entitled Standard Minimum Rules.

In 1990, the proposal to elaborate Standard Rules on the Equalization of Opportunities for Persons with Disabilities was accepted, and the Rules were adopted in 1993 (UN, 1993). The Rules were not legally binding, but they were developed within the context of individual rights for persons with disabilities.

In 22 different areas, including education, legislation, and rehabilitation, concrete measures were formulated. The role and responsibility of the State were strongly emphasized. A specific principle embraced throughout the document was the involvement of organizations representative of persons with disabilities in all matters concerning their lives.

One of the most important features of the Standard Rules was the establishment of an active and independent monitoring mechanism. This consisted of a special rapporteur and a panel of experts, the majority of which were to be selected from DPOs. Bengt Lindqvist, former Swedish Minister for Social Services and Family Affairs, was appointed in 1994 as the first special rapporteur and held this position until 2002. The panel was constituted by the six most influential international disability organizations. Their cooperation in the panel resulted in the formation of the International Disability Alliance (IDA) a few years later.

Several governments contributed funding in support of the monitoring activities. This meant that the special rapporteur could travel extensively and visit a number of countries each year. He also carried out three separate global surveys to find out more about the situation of people with disabilities around the world. In this way, information was collected in 130 countries in all parts of the world. The panel of experts met once a year to consult with the rapporteur. Over the next few years, a number of countries adopted new disability legislation and made other policy changes in harmony with the Rules. There is no doubt that the Standard Rules contributed to the recognition of disability as a human rights issue and strengthened the arguments for a future UN convention.

Two Other Important Steps Forward

In 1992, Leandro Despouy, the special rapporteur appointed some years earlier within the human rights system, delivered his final report, *Human Rights and Disabled Persons* (Despouy, 1992). He recommended that the UN should accept disability as a human rights concern and consider establishing either a Disability Ombudsman, which could bring forward violations of human rights caused by the existence of a disability to the appropriate monitoring committee, or a special convention on the rights of people with disabilities. His recommendations were of great importance for further development in the field.

Another very important step toward recognizing disability as a human rights concern for the UN was taken when, in 1994, the Committee on Economic, Social and Cultural Rights (CESCR) issued General Comment No. 5, which deals with disability from a human rights perspective (CESCR & OHCHR, 1994). This general comment can be seen as a response to the statements in the World Programme adopted more than ten years earlier.

After these events in the early 1990s – the Standard Rules, the report by Despouy, and the General Comment by CESCR – the issue of disability was brought to the full attention of the UN Commission on Human Rights, the highest UN body in the human rights field. In a series of resolutions issued from 1996 to 2002, the Commission decided that disability should be fully recognized as a human rights concern for the UN and all its human rights bodies. These resolutions constitute the final recognition that disability matters have an obvious human rights dimension and that the issue must be included in the UN human rights monitoring system.

A Special Convention

Representatives of DPOs were enthusiastic about this development, but at the same time, a discussion started about how this breakthrough would be best utilized. The Special Rapporteur on the Standard Rules took two initiatives in this context. He prepared a working document for the panel, in which he outlined a number of possible ways to act (Lindqvist, n.d.). In one of these suggestions, he asked the panel to consider the development of a special convention with an independent monitoring mechanism. Most of the panel members were in favor of this solution, as, in their opinion, it represented the most efficient way to get results. They brought this initiative back to their organizations and undertook activities to promote the idea.

One of the panel members, Maria Eugenia Antunez of Mexico, presented the idea to the Mexican President Vicente Fox. In September 2001, President Fox, in his main speech to the General Assembly, formally proposed a Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities. His proposal led to the creation of a working group to consider the proposal (Rioux & Carbert, 2003). The contributions by representatives of disability organizations were significant in the elaboration of the convention. The new UN Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the General Assembly in December 2006 (UNEnable, 2006b).

The other initiative taken by the special rapporteur was to organize a seminar consisting of DPO representatives, human rights activists, and representatives from the UN. During one hectic week in November 2000, the participants discussed ways to utilize the CRPD in the struggle to improve living conditions for persons with disabilities.

In the final report of the seminar, entitled *Let the World Know* (Lindqvist, 2001), plans to make monitoring relevant, comprehensive, and efficient for the disability field were presented. The report recommended that monitoring should take place in three different areas: systemic monitoring, including government policy and legislation, case law, and service provision; monitoring individual experiences of discrimination and exclusion; and monitoring the depiction of disability in the media. It was strongly recommended that disabled persons themselves and their representative organizations play a leading role in all of these forms of monitoring. Capacity building among DPOs in the field of human rights was strongly recommended. These recommendations by the seminar constituted the basis of the Disability Rights

Promotion International (DRPI) project, the purpose of which is to develop monitoring and training tools in these areas. This project started in 2002 and continues today.

As mentioned before, in 2001, the Mexican government proposed that a special disability convention should be elaborated. This idea was accepted by the General Assembly, and a process to elaborate such a convention was immediately initiated. A drafting committee was formed by interested state parties, and civil society was permitted to attend and take part in the drafting to an extent that was unique for this kind of UN work. Representatives of international disability organizations actively participated in the drafting and had a significant impact on the content of the convention.

The drafting committee worked and completed a proposal for a Convention CRPD in 2006. The General Assembly adopted the CRPD the same year.

The CRPD contains two remarkable features that are not spelt out as clearly in any of the earlier UN core conventions. Both of these features concern the methodology of monitoring. Those who have worked in monitoring the implementation of human rights conventions over a long period know these conventions can lead to changes in the existing national legislation. For me as Special Rapporteur on Disability, it was important to make the phenomenon of disability visible within each country's legislation. This would offer a solid base of work in efforts to improve living conditions. However, such new laws do not automatically affect the living conditions of the people concerned. This is where different forms of monitoring progress are indispensable in providing evidence of the actual situation. The effects of new legislation and policies must be continuously analyzed and brought to the attention of governments and international monitoring mechanisms. The closer you can get to the "grassroots" in exploration and evidence-based knowledge, the better.

One unique feature of the CRPD is that every nation must establish a national monitoring mechanism in the field of disability to collect information and evidence of remaining problems (UNEnable, 2006b, art. 33). Unfortunately, many governments have not yet established a mechanism in harmony with the provisions of the CRPD, despite the fact that several years have passed since it came into force in 2008.

The other important feature of the CRPD is the emphasis on the involvement of disabled persons themselves and their representative organizations in the national monitoring process. Unfortunately, many governments have not yet established a structure that offers an active role for DPOs.

These new signals from the UN human rights system are important. They open a whole new field of methodological and structural development. They offer a challenge to all of us involved in the struggle for better living conditions for people with disabilities. (Lindqvist, 2015).

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2020 Pandemic and Refugees with Disabilities

5

Ron C. McCallum AO

Contents

Abstract

The first 6 years of the work of the CRPD Committee forms the backdrop of this chapter. Its focus turns to the 2020 pandemic and refugees with disabilities. The pandemic showed that persons with disabilities were a vulnerable population. Article 11 of the CRPD applies to emergencies. The work of the UN Special Rapporteur on disability and of the Australian Government is noted. Refugees with disabilities are sometimes forgotten. The obligations in the CRPD extend to all persons resident in a country. Research is unpacked which shows that 15% of refugees have disabilities, and that protective measures are essential.

My premature birth took place in Melbourne, Australia, some 71 years ago. The use of pure oxygen to save my life caused me to be blind from birth. I suffer from retrolental fibroplasia, which is better known as retinopathy of prematurity (Brown, Establishing proof. Washington Post, 2005). My career was in legal academia, which culminated with my appointment in 1993 as Professor of Labor Law at the University of Sydney. This was the first occasion in which a totally blind person was appointed to a full professorship in any field at any Australian or New Zealand university. From 2002 to 2007, I undertook my 5-year term as Dean of Law at the University of Sydney (McCallum, Born at the right time: A memoire. Allen and Unwin, Sydney, 2019).

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My work in the field of disability was largely concerned with the welfare of blind and vision impaired Australians. For example, in February 2006, I was appointed to the Board of Vision Australia which assists blind and vision impaired Australians. My term concluded in October 2015. However, after Australia ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) on 17 July 2008, the Australian Government asked if I would stand as a candidate for election to the United Nations Committee on the Rights of Persons with Disabilities (CRPD Committee) which monitors the implementation of the CRPD. At the United Nations headquarters in New York on 3 November 2008, I was elected as an inaugural member of the CRPD Committee and served for 6 years until my mandate concluded on 31 December 2014. (I was initially elected for a 2-year term in accordance with article 34(7) of the CRPD and was subsequently elected for a further term of 4 years on 1 September 2010.) It was my honor to serve as the Chair of the CRPD Committee from February 2010 to April 2013. When my period as Chairperson concluded, I remained a Vice-Chairperson of the CRPD Committee until the end of my mandate. It was a further honor to be the Chairperson of the Committee of the Chairpersons of the United Nations Human Rights Committees from July 2011 to June 2012. The early years of the CRPD Committee gave me a broader perspective of the plight of persons with disabilities throughout the world. It was a privileged position because I was able to read reports and participate in constructive dialogues where the day-to-day difficulties confronting persons with disabilities in many countries were revealed and discussed. During my tenure as Chairperson, the first constructive dialogue with Tunisia took place in 2011 (CRPD, Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Tunisia, fifth sess, UN Doc CRPD/C/TUN/CO/1, 2011), and in the following year, there was a fruitful constructive dialogue with the People's Republic of China (CRPD, The Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of China including Hong Kong and Macao, eighth sess, UN Doc CRPD/C/CHN/CO/1, 2012 (China)). Also, in 2012, the first complaint under the Optional Protocol to the CRPD was determined (MH v Sweden). The Optional Protocol to the CRPD entered into force for Australia on 20 September 2009.

In 2014, the CRPD Committee published its first two general comments on article 12 on equal recognition before the law (CRPD, GC No 1) and on article 9 concerning accessibility (CRPD, GC No 2).

The CRPD: A Game Changer

The CRPD is a game changer because it has placed the human rights and inherent dignity of persons with disabilities squarely within the human rights framework of the United Nations. One hundred and eighty-one countries have ratified or acceded to the CRPD, and 96 nations have ratified its Optional Protocol. As the 2011 World

Bank and World Health Organization *World Report on Disability* shows (WHO, 2011, Ch 2), persons with disabilities comprise 15% of the world's population. In other words, there are approximately one billion of us persons with disabilities. However, this World Health Organization and World Bank Report also makes it clear that disability is synonymous with poverty in most nations. This is because so many persons with disabilities lack education and opportunities for employment and are unable to access appropriate health and community services.

Having regard to the constructive dialogues of the CRPD Committee, it is apparent that whether nations are developed or developing, the same issues concerning people with disabilities arise. One notable issue is violence, including sexual violence, against women and girls with disabilities in institutional settings and/or the family home. Likewise, many persons with disabilities around the world are still unable to access quality inclusive education and the levels of unemployment are still too high in most countries. In many nations, guardianship and mental health laws still do not establish regimes of supported decision-making to assist persons with disabilities to make decisions in accordance with their will and preferences.

The COVID-19 pandemic and the plight of refugees with disabilities are topical issues at the time of writing and thus the role of the CRPD deserves brief comment.

The COVID-19 Pandemic and People with Disabilities

Article 11 of the CRPD requires governments to prepare and take "all necessary measures to protect and to keep safe persons with disabilities when humanitarian emergencies, natural disasters or armed conflicts occur." It is clear that in emergency situations, women, children, and persons with disabilities are especially vulnerable (Hart et al., 2014, p 148; Karr & Mitchell, 2014). By March 2020, the COVID-19 pandemic had begun to spread throughout the globe. Persons with disabilities, especially in institutions, are especially vulnerable due to the highly contagious nature of the virus and their need for close contact with carers. The United Nations Special Rapporteur on the Rights of Persons with Disabilities, Ms. Catalina Devandas-Aguilar, on 16 March 2020, released a statement requesting governments to assist persons with disabilities at this troubled time (UN Special Rapporteurs and Independent Experts, 2020).

In 2019, an inquiry was established by the Government of Australia to examine violence, abuse, neglect, and exploitation of people with disability. In Australia, these inquiries are known as royal commissions. The Disability Royal Commission was established on 4 April 2019 (DRC, 2019). On 26 March 2020, this very inquiry issued its own Statement of Concern about the impact of COVID-19 on persons with disabilities (DRC, 2020). The Australian Government (DRC Response, 2020) and other governments around the globe have put in place measures to assist persons with disabilities, and it is hoped that these measures assist the community to protect vulnerable groups including persons with disabilities throughout the duration of this pandemic.

The Plight of Refugees with Disabilities

There are 79.5 million people around the world who have been forced to leave their homes who are in need of protection. They include 26 million refugees, half of whom are under 18 years of age (UNHCR, 2020). It is clear that the rights and obligations contained in the CRPD are not limited to citizens or permanent residents of ratifying countries. The CRPD protects all persons with disabilities within the territory of countries which have signed up to the CRPD (Crock et al., 2012), 738–742). Therefore, all displaced persons are entitled to CRPD protections and cannot be discriminated against when on the territory of a ratifying nation. Of course, international human rights and refugee law prevents nations from returning persons to places where they risk being persecuted or tortured (Saul, 2010, pp. 63–104, p. 71 (citing UN Human Rights Committee (1989), General Comment No 18, 'Non-discrimination', 37th sess, UN Doc HRI/GEN/l/Rev.5 (29 May 2008)). Refugees with disabilities are a particularly vulnerable group to mistreatment. Together with my wife, Professor Mary Crock, and two colleagues, Dr. Laura Smith-Khan and Professor Ben Saul, we undertook research from 2011 to 2016 on refugees with disabilities in six countries: Malaysia, Indonesia, Pakistan, Uganda, Jordan, and Turkey. We concluded that within the refugee population, at least 15% of refugees are persons with disabilities (Crock et al., 2017, Ch 4). The difficulty in identifying refugees with disabilities and extending them appropriate care was apparent from our research (Crock & Smith-Khan, 2017, Ch 16, p. 305). Much more needs to be done to ensure that refugees with disabilities have access to services and to education, and are able to participate in resettlement programs.

In conclusion, the CRPD Committee performs its tasks remarkably in the international arena. However, it is essential for persons with disabilities, organizations, and national human rights institutions to remain vigilant and hold ratifying governments to the rights and obligations set forth in the CRPD.

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Part II

History of Disability

Disability History: Introduction

6

Sara Scalenghe and Geoffrey Reaume

Abstract

This introduction offers a succinct overview of the five chapters contained in the History of Disability section of this handbook and highlights their contributions to the field of disability history. It also briefly addresses the Euro-American centrism of the field and the issue of the dearth of historical scholarship on disability from and about the "Global South," especially in the premodern period.

Introduction

Disability history has seen what historians Daniel Blackie and Alexia Moncrieff have recently described as "tremendous growth" during the early twenty-first century (Blackie & Moncrieff, 2022, 1). This developing area of study has evolved out of the field of Disability Studies and the activism of disabled people throughout the world as part of the wider civil rights struggles of marginalized communities (Rembis et al., 2018). Part of the way in which this struggle has been manifested is through the wider efforts of scholars and activists who have worked to ensure that the academy and broader public be aware of the diverse, complex histories of people who are now defined as disabled in various cultures throughout history. In doing so, historians are seeking to understand this topic from the perspectives of disabled people, and where this is not possible due to the absence of primary sources, from a critical disability historical perspective where the vast experiences of physical, mental, and sensory impairment are not reduced to contemporary medical

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interpretations but are instead placed in the social and cultural contexts of their times. The articles contained in this section contribute to these efforts. The authors describe historiographical and methodological developments which have made disability history so very path-breaking in how people have come to understand and experience disablement in so many different ways down through the ages.

In his article covering the most distant period in this collection, "Prosthetics for Osiris: Evidence for Assistive Technology in Ancient Egypt," Jonathan White-Boonshoft describes how ancient Egyptians created assistive devices and prosthetics both for the living and for the dead on what was expected to be their journey to the afterworld. The images included in this essay contribute significantly to illustrating the archaeological remains that are described in the article and point toward an innovative way of understanding disability's ancient history. This is accomplished through the use of evidence uncovered and interpreted by archaeologists about what it was like to be physically disabled several thousand years ago. As White points out, prosthetic devices were meant for practical purposes as well as, in some cases, decorative design. From evidence such as walking sticks, prosthetic body parts, to artistic reliefs and hieroglyphic script, White uses a broad range of archeological sources to highlight a history that is as old, and even older, than the pyramids. In doing so, his study demonstrates that physically assisting or "correcting" an impairment was a common practice of varying degrees among both rich and poor, though obviously the quality of such devices and prosthetics varied greatly depending on social status.

In "European Medieval Disability History: An Overview," Ninon Dubourg provides a historiographical discussion of disability in medieval Europe, particularly during the period from the twelfth to fourteenth centuries. Dubourg's overview of recent scholarship shows the position of disabled people during this period as being more than scorned and harassed but also as integrated and more widely accepted as part of the fabric of the late Middle Ages than is often assumed. It is particularly important that her review outlines the increasing level of historical scholarship on medieval European disability history since 2005, which has enriched our knowledge of the complexity and diversity of this topic beyond the image of disabled people as primarily beggars who were cast out by society. Her discussion of the context of poverty in medieval Europe helps to explain this history further, particularly in regard to disabled people as the focus of miracle hagiography and subjects of charity. As with White's article on disability in Ancient Egypt, Dubourg includes images to illustrate the points made in her article, in this case about charity and hierarchy, mockery and inclusion, and assistive devices for a rich disabled person. Her discussion of how scholars have shown the ambiguity of disability during this period, wherein disabled people were both mocked and socially integrated, provides an essential contribution to the complexities of disablement and its depiction during medieval European history.

Historiographical developments are also the focus of "Disability in US History" by Caroline Lieffers. Her article emphasizes the burgeoning histories of disability in Indigenous, colonial, and African-American enslaved societies that, until recent years, had been neglected among disability scholars based in northern countries.

The growing field of studies on racialized people provides a more representative history of disability, as Lieffers indicates. She also describes disability histories focusing on the impact of industrialization and eugenics on disabled people, along with disability rights activism since the latter half of the twentieth century. Her article provides an overview of some of the most important new disability history work appearing in the United States, which has expanded the field beyond asylums and well-known individuals to include wider social dimensions of disablement.

Wei Yu Wayne Tan's "Disability History of Modern East Asia: An Overview" shifts the focus away from Europe and the United States. Blackie and Moncrieff have recently pointed out that much of the scholarship on disability history is now being published in languages other than English (Blackie & Moncrieff, 2022, 1). Although it is a welcome development, those languages are usually European, and the field is still overwhelmingly centered on Europe and North America. The dearth of scholarship about the rest of the world, and especially about and *from* the "Global South" (a problematic term, to be sure) remains the Achilles' heel of the field. This dearth of research is even more pronounced for the premodern period; to date, there exists only a handful of historical monographs on disability in the non-Western world before the nineteenth century (see, for example, Tan, 2022; Scalenghe, 2014). The overwhelming focus on Europe and North America is a problem when one considers that up to 80% of the world's disabled people *do not* live in Europe or North America. Thus, most of the historical scholarship currently available is about a small portion of the world's modern population and cannot give us an accurate picture of how disabilities have been lived by human beings throughout history. Rather, it is largely the experiences of (mostly white) Europeans and North Americans that are represented. Perhaps inevitably, then, it is (mostly white) European and North American scholars that are framing the agenda and priorities of the field. But even some of the debates about identity-first versus person-first language do not always translate or resonate in non-Western contexts.

Why is there less historical scholarship on disability about or from the "Global South," especially in the premodern period? The answer depends, of course, on the specific country or region – the Democratic Republic of the Congo, for example, is obviously very different from Bangladesh or from Syria – but there are some shared similarities. At the practical level, it can be challenging and time-consuming for historians to find, access, and process archival and other primary sources, which are often unpublished and uncatalogued. Even native speakers may require specialized language training. For scholars who are based in the "Global South," where institutions of higher education are often massively underfunded, there are additional obstacles, such as the lack of resources, and the lack of exposure if the scholarship is not written or translated in European languages. However, there are many other reasons why there are still few works centered explicitly on disabled people, including the dominance of the medical model of disability and the still widespread societal stigmatization of disabilities, especially congenital and intellectual or cognitive ones. On a more positive note, however, there is exciting new work in the pipeline. Tan's article in this collection is a good example of what non-Western disability history can contribute to this conversation. It provides a much-needed survey of disability history in China, Korea, and Japan since the nineteenth century with a succinct discussion of such a broad topic in three countries over a long period, covering science, medicine, law, activism, and popular culture. The brief summaries of wider political developments help to place this history into a broader national and international context. Tan's piece highlights how terminology and ideas about what is meant by disability are based on cultural influences and external factors. Underlining the distinctions, as well as similarities, between ancient cultures in all three countries, Tan discusses tensions between Chinese, Korean and Japanese ideas around what we now call disability with imported western practices in which medical model treatments often reflected anti-disability biases of practitioners.

Last but not least, in "Transnational History of Disability: Reflections," Gildas Brégain analyzes the strengths and problems with transnational history, as it applies to disability history. In particular, he underlines the need for Western (particularly Anglo-Saxon) historians to think far beyond national borders as defining what is original in activist and legislative developments to broaden the scope of disability history in regard to the "Global South." While discussing historiographical developments, Brégain addresses some of the methodological, language, and financial issues historians will encounter when undertaking transnational disability history. This includes the difficulty of doing social history from below through transnational history, as can be done through more localized histories. He also reflects on how few disability historians are engaged in transnational history and yet how many younger historians are under pressure to consider doing transnational history. Brégain's suggestion of possible solutions to this challenge are to engage in micro-history (rather than the more common macro approach) as being more practical, and for some a more affordable solution to this challenge of how to do transnational disability history.

Together, the articles included here reveal the extent to which disability history continues to re-shape our understanding of the experiences of impairment in ways that demonstrate both how much this history changes our understanding of the past as well as how much more there is to uncover and re-interpret from the perspectives of disabled people.

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Prosthetics for Osiris: Evidence for Assistive Technology in Ancient Egypt

7

Jonathan Boonshoft-White

Contents

Abstract

Recently there has been an increasing trend to interpret disability as a part of personal identity rather than a condition or conditions to be suffered. Recognizing the diversity of approaches to indfigividual abilities and the variety of cultural viewpoints surrounding disability, it is time to examine how people with disabilities were perceived and how they perceived themselves in the ancient world. The large number of available remains, rich material culture, and existing written and visual records make Egypt an excellent case study for exploring individual and cultural perceptions of ability, disability, and accommodation in the past. This chapter reviews extant finds in order to critically examine material evidence for disability and accommodation among elites from various periods of Ancient Egypt. The material culture shows how people who might be recognized as having physical disabilities today were accommodated in Ancient Egypt. Accommodations range from simple canes to more complex walking devices. Perhaps most striking is the presence of some of the earliest prosthetic devices in Egyptian burials. These prostheses can be merely ornamental or fully functional and were clearly made to aid not only in life, but also in the afterlife. Together with

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paleopathological evidence of disability during life provided by mummified human remains, these individuals and their burials offer a revealing glimpse into what it was like to live and die with a disability in the age of the Pharaohs

Introduction

Recently (that is, within the last 30 years) there has been an increasing trend to interpret disability as a part of personal identity rather than a condition or conditions to be suffered. Recognizing the diversity of approaches to individual abilities and the variety of cultural viewpoints surrounding disability, the field of critical disability studies developed in the 1980s to counter the then-prevalent medical model of disability (Mitchell & Snyder, 2004: 16–25, Linton, 2010: 149). Disability scholars argue that even though there is considerable overlap between medical conditions and disabilities, a medical model is inadequate for understanding disability on many levels (Davis, 1997: 1–5). Disability is also culturally and socially constructed, varying greatly from culture to culture and even social group to social group (Mitchell & Snyder, 2004: 5). It is this dichotomy – that disability is both tangible and intangible – that makes it both difficult and fascinating to examine in archaeology and history.

In keeping with the move away from the medical model, this chapter pivots away from bioarchaeology, paleopathology, and extensive textual analysis to put the focus on what material culture can tell us about disability, specifically disability in Ancient Egypt. Most of the material culture examined herein dates from the New Kingdom (c.1550–c.1077 BCE) and Third Intermediate Period (c. 1069–c.664 BCE). Art from the Old (c. 2700–c. 2200 BCE) and Middle Kingdoms (c. 2055–1650 BCE) will be examined as well. Accommodations range from simple canes to more complex walking devices. Perhaps most striking is the presence of some of the earliest prosthetic devices in Egyptian burials. These prostheses can be merely ornamental or fully functional and were clearly made to aid not only in life, but also in the afterlife. Together with paleopathological evidence of disability during life provided by mummified human remains, these individuals and their burials offer a revealing glimpse into what it was like to live and die with a disability in the age of the Pharaohs.

Definitions

Three terms need to be defined before proceeding: **disability**, **accommodation**, and **assistive technology**. A **disability** is defined by Merriam-Webster as “a physical, mental, cognitive, or developmental condition that impairs, interferes with, or limits a person’s ability to engage in certain tasks or actions or participate in typical daily activities and interactions.” The Oxford Dictionary offers the similar “physical or mental condition that limits a person’s movements, senses, or activities,” while also offering “a disadvantage or handicap, especially one imposed or recognized by the law" (Merriam-Webster.com *Dictionary*, s.v. "disability," accessed December 1, 2021, https://www.merriam-webster.com/dictionary/disability).These dictionary definitions are based primarily on a medical model of disability, that is, rooting the concept of disability in medical or biological conditions or states. Disability studies recognizes additional models and constructions of disability, namely those based around culture or society. In these models, disability is defined as much by what a culture perceives, or a social group determines is a disability. The limitations a person faces are therefore not automatic limitations posed by a medical condition but constructed limitation imposed by culture and/or society. For example, in most modern societies, myopia (near-sightedness) is not considered a disability, even though it is clearly a medical condition that impairs, interferes, and limits a person's ability to engage in certain tasks or actions. This is because, for a variety of reasons, myopia does not fit with these societies' cultural constructions of "disability." When attempting to examine disability archaeologically, the medical model provides a useful starting point for analysis, but it is the cultural constructions of disability that the archaeologist is more interested in.

An **accommodation** is a change or adjustment to a job, work environment, or the way things are done that would allow an individual with a disability to enjoy the same accessibility that a person without a disability would enjoy. To put it more simply, accommodations are the media through which accessibility is achieved. Generally, if something is universally designed, it will not require an accommodation to make it accessible. Examples of accommodations, in a general sense, range from extended time on exams to prosthetic limbs (Williamson, 2020: 3, 7, 9, 57, 6–66).

This brings us to the final term, **assistive technology**. In a broad sense, anything that is used to deliver an accommodation to a person with a disability is a form of assistive technology. The most obvious forms of assistive technology devices that are specifically designed for disability accommodation are cochlear implants, prosthetic limbs, and wheelchairs. However, technology that was originally designed for other purposes, such as text-to-speech software, voice activation ("hands-free") technology, tape recorders, and typewriters, can also be used as assistive technology (Guffey & Williamson, 2020: 7).

Mobility Aids as Assistive Technology

Mobility aids are simple or complex pieces of technology that assist in locomotion. They are arguably the most common and the most recognizable form of assistive technology. In modern times, the wheelchair is the most recognizable mobility aid, followed perhaps by the walker. Archaeological evidence for wheelchairs or any sort of wheeled furniture is sparse. In Classical (510–323 BCE) Greek vase paintings, the god Hephaistos and the demigod Triptolemus are occasionally shown in wheeled chairs or one-person chariots pulled by flying serpents (Anderson, 2013; Wheelchair Junkie, 2021), but these scenes are firmly mythological and there is no material or textual evidence to suggest that such conveyances were actually made by the Ancient Greeks. A tomb carving from Ancient China also seems to show a wheeled chair used for moving a person (Anderson, 2013). However, this carving seems to be referenced only in popular press and not any academic source. These popular sources cannot agree as to whether the carving dates from the sixth century BCE, which would place it at the height of the Spring and Autumn Period (771–476 BCE), or the sixth century CE, which would date it to the Northern and Southern Dynasties (420–589) or Sui Dynasty (581–618). Again, there are no contemporaneous texts mentioning wheelchairs, nor have the remains of any such conveyances been found. The earliest verifiable material and textual evidence for wheelchairs date to seventeenth-century Europe (Bellis, 2019; Nias, 2019). It is not surprising, therefore, that there is no evidence for wheelchairs in Ancient Egypt. However, material evidence for simpler mobility aids can be found in the archaeological and art historical records.

Sticks and Staves

The simplest form of mobility aid is a humble stick, and from the stick emerged the staff and the cane. Although some studies exist that purport to find the earliest evidence for canes in Egypt, they miss the point somewhat, as the use of a stick of some sort for mobility stability surely predates Ancient Egypt and probably goes back as far as behaviorally modern humans. The questions that should concern us regarding the use of canes are not simply “when?” and “where?”, but “why?” and “how?”

In modern times, most individuals who need to use canes might be considered “elderly” rather than “disabled,” and textual evidence for association between staves and old age is abundant in Ancient Egypt too. Hassan (1976: 114–199) describes two sticks of the New Kingdom that each bear an inscription wherein the deceased owner is addressing his staff saying, “Come my staff, I lean on you.” In one of them, “when I have grown old” is added. In his *Maxims*, the vizier Ptahhotep said, “May this servant be ordered to make a Staff of Old Age” (Loebl & Nunn, 1997; Lichtheim, 1973: 63). However, the underlying reason for the cane – a mobility problem – would be considered a disability in a younger person, at least by today’s standards. In the case of the elderly, the mobility problem is the disability, the cause of this disability is age, and the accommodation is a cane or staff. Therefore, the following discussion of sticks and staves in Ancient Egypt is divided into “artistic” and “practical,” and not “disabled” and “elderly.”

For the purposes of this discussion, a “staff” (pl. “staves”) is a stick that comes at least to the shoulder of its user, while the term “cane” will be used to describe a stick that only comes up to waist level.

Artistic Depictions of Canes and Staves

Within Egyptian art, obvious depictions of staves as mobility aides are rare. Egyptian art of most periods is highly stylized, with specific imperfections completely ignored. It is much more common to see staves used as symbols of authority. Nonetheless, there are a few artistic examples that hint at the reality behind the style.

The most familiar of all staves in Egyptian art is probably the *was* staff. This staff is held almost exclusively by divine figures – pharaohs and priests are the only humans shown using them. The *was* is a modification of the hieroglyph for "power" or "dominion," held in one hand while *ankh* ("life") is held in the other. For humans with more secular roles, the *medu* staff is much more common. Although the *medu* is occasionally shown as a walking stick, it was primarily an authority symbol, to the extent that it became a hieroglyphic determinative in the words for "official," "noble," and "courtier" (Fischer, 1978: 7–8; Loebl & Nunn, 1997: 450).

There is a tradition of showing the *medu* in a more complex way, however. In several images, the *medu* is held with both hands, one grasping the top, the other resting against it at the level of the thigh. One leg is in front, with the forward leg slightly bent at the knee with the heel clear of the ground (Fig. 1, left). Although this posture is usually referred to as a "posture of leisure," Loebl and Nunn (1997: 452) propose that it represents the stance an individual would have to assume to compensate for a painful condition of the hip, the knee, or even the heel, meaning that some depictions of the *medu* may represent mobility aids. Relatively early examples of this include images from the tombs of Ra-khaef-ankhu (Fig. 1, center) and Mer-ibi (Fig. 1, right), both officials who lived during Dynasty IV (c. 2550) and were buried in the Giza Necropolis. The stela of Intef, an "overseer," dated to Dynasty XII (c. 1991 BCE–c. 1802 BCE), shows a similar posture. Intef's stela seems to show signs of apparent wasting or heavy wrinkling in both legs (Loebl & Nunn, 1997: 451). Derry (2013: 436–58), assuming that the image is a portrait of Intef himself, suggested that the official specifically suffered from hydrocephalus due not only to the state of his legs but also the apparently enlarged head. Interestingly, the stela of another Intef, this one a military overseer and also dated to Dynasty XII, features a male figure with emaciated limbs, seemingly wrinkled skin, and a comparatively large head (Fig. 2). Although the man holds his *medu* more traditionally,

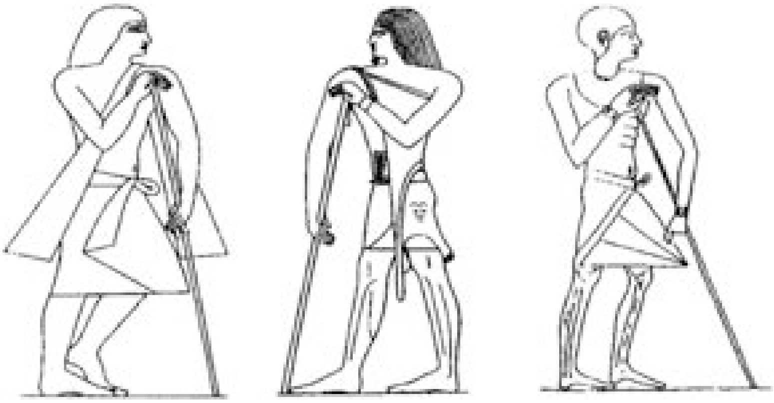


Fig. 1 Left: so-called position of leisure with one heel off ground, from the east wall of tomb of Ra-khaef-ankhu in Giza, Dynasty IV (c. 2550 BCE). Center: alternative so-called position of leisure with both heels on the ground, from the tomb of Mer-ibi in Giza, Dynasty IV–V (c. 2500 BCE). Right: posture of leisure with both heels on the ground, but with legs that appear wasted, from the Stela of Intef, Dynasty XII (c. 1900 BCE), British Museum EA 562. (Photo: © Loebl and Nunn 1997, after Harpur 1987)

Fig. 2 A very thin man holding a *medu* and leading a cow. From the stela of Intef, Dynasty XII. Metropolitan Museum of Art 57.95. (Photo: Metropolitan Museum of Art, Open Access)

he is leading a cow with the other hand, suggesting that he may still need the staff for support. Epstein (1937: 304–313) also described an example of this posture from the tomb of Harkuf and wondered whether the flexed knee indicated an injury. However, Epstein mistook a crack in the surface of the relief for an axillary horizontal piece at the top of the staff and erroneously identified it as the earliest recorded crutch (Loebl & Nunn, 1997: 451).

Another nonstandard depiction of the *medu* occurs in the tomb of Menna, a scribe of Dynasty XVIII. In the image, an elderly balding haired man (Fig. 3) oversees some agricultural activity. It can be interpreted that this is an elderly farm laborer suffering from osteoarthritis promoted to overseer. The canons of proportion and style that governed funerary art might not have been so strictly implemented for a servant as they would have been for the tomb owner. Thus, this image may well be a realistic depiction of an elderly man with fixed flexion deformity of a lower limb joint (Loebl & Nunn, 1997: 452) (Fig. 4).

Of slightly later date is the funerary stele of Roma, a doorkeeper of Dynasty XVIII or XIX (Fig. 5). Roma's depiction features a withered right leg that is clearly and deliberately depicted as being thinner and shorter than the other. Roma is in an offering pose, with both his hands otherwise engaged, so his staff is nestled between his chest and his left arm, and thus the image doesn't show him using it to walk. Still, the image is a rare and striking depiction of physical difference and nestling a staff between the chest and an arm is certainly a natural way keeping the staff upright when one's hands must both be otherwise engaged (Loebl & Nunn, 1997: 454).

From roughly the same time, but at the other end of the social ladder, is a carved and painted limestone (Fig. 6) from the Amarna Period, said to be from Tell el-Amarna (Aldred, 1991: 287). The limestone depicts a pair of well-dressed Egyptians apparently at leisure. The woman wears a diaphanous gown and holds flowers in each hand, while the man wears a lavish kilt and leans on a long, thin stick, similar in size to a *medu*. His right arm is wrapped around it, awkward but clearly supportive. Contextually, it is not clear whether the male is leaning on the stick out of necessity or leisure, but the fact that he is shown with it in either context is

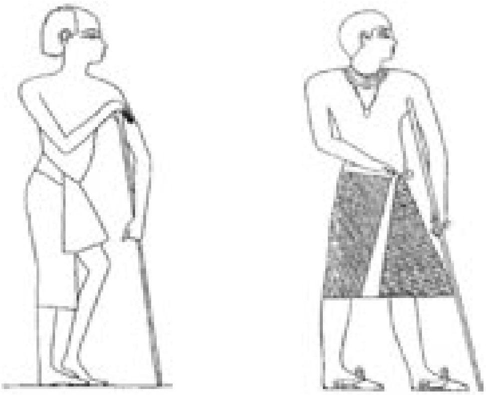
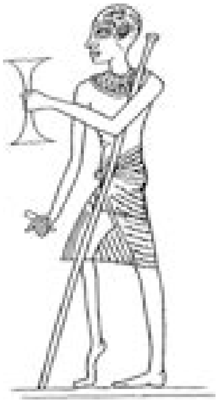


Fig. 3 Left: a servant, balding and apparently aged, overseeing agricultural activities while resting on his staff, from the tomb of Menna, (TT 69) at Sheikh Abd el-Qurna, Dynasty XVIII (c. 1400 BCE). Right: Tomb owner leaning on his staff which is tucked into his axilla. From the tomb of Nefer in Saqqara, Dynasty V, (c. 2400 BC). (Photo © Loebl and Nunn 1997, After Harpur 1987)

Fig. 4 Roma, a doorkeeper of Dynasty XVIII or XIX, c. 1300 BCE. From his stela in the Carlsberg Glyptotek Museum, Copenhagen, AIN 134. (Photo: © Loebl and Nunn 1997, after Harpur 1987)



quite striking. Amarna Period art is generally accepted to focus on realistic or even truthful depictions of individuals, so this is often interpreted as being a literal image of an aristocrat using a cane. It has been suggested that the pair are Tutankhamun and Ankhesenamun due to their resemblance to the couple on Tutankhamun's famous throne. Furthermore, the slab closely resembles an ivory from his tomb (Fig. 6) that seems to show the couple in an almost identical physical arrangement – and in which Tutankhamun is holding what is more clearly recognizable as a *medu*.

Actual Canes and Staves

Tutankhamun, the famous "boy king," had over 130 canes and walking sticks entombed with him, most of them in the antechamber (Fig. 7). As he died in his late teens, they

Fig. 5 Limestone portrait thought to depict Tutankhamun and Ankhesenamun, Dynasty XVIII, c. 1330 BCE. Said to be from Tell el-Amarna. Neues Museum, Berlin. (Photo: © A. Praefcke, Wikicommons)

were clearly not needed to support an elderly man. Most of them are around a meter in length, and many of them are crooked on one end. If not for their ornamentation and provenance, they could be mistaken for modern canes. Since their discovery, debate has raged as to whether the young king had used them. Many of them are covered in gold leaf and various forms of precious inlay, and several feature handles carved in the shapes of non-Egyptian peoples (Fig. 8). Howard Carter remained baffled by them and suggested that Tutankhamun must have been an amateur collector of such things (Burzacott, 2016). Another suggestion was that the canes were used nonpractically, and the curved handles depicting non-Egyptian peoples were supposed to be placed on the ground and pressed into the dirt, symbolically stomping Egypt's enemies into the dust. This suggestion was found credible by the authors of the Tutankhamun's Sticks and Staves Project (TSS), who point out that the papyriform knobs at the blunt end of the canes bear the pharaoh's cartouche, and therefore would not have been suitable for putting on the ground (Veldmeijer & Ikram, 2020: 12). However, the anthropomorphic handles show few signs of wear and tear, and no evidence for such a practice has been found, either in Tutankhamun's tomb or elsewhere.

As for Carter's assumption, subsequent research has all but disproven it. Tutankhamun's mummy was examined many times, and modern paleopathology and imaging techniques confirmed that Tutankhamun had had a visible clubfoot (Hawass et al., 2010: 645). This means that he probably would have needed a walking stick when he was alive, which implies that the canes in the tomb were

Fig. 6 Ivory inlay portrait of Tutankhamun and Ankhesenamun on the lid of a coffer, Dynasty XVIII, c. 1330 BCE. From the tomb of Tutankhamun (KV62). The Grand Egyptian Museum, Cairo. (Photo: © Egyptian Museum, Cairo)

not curios or a rushed attempt to fill the tomb, but things he might have used. This, along with the ivory lid, makes it more likely that the painted relief from Tell el-Amarna discussed above does in fact depict him. The authors of the TSS project, however, disagree, as their detailed examination shows that even the simplest and sturdiest of Tutankhamun's canes have little evidence of hard use, even taking account the fact that he may have used them mostly indoors (Veldmeijer & Ikram, 2020: 12). However, I argue that the sheer number of walking sticks might explain the lack of use wear. Even if Tutankhamun used every stick in the tomb, he would still have only used each one three times a year. Another possibility, consistent with the findings of the TSS project, is that Tutankhamun's clubfoot was visible enough that he would receive canes as gifts or that his attendants kept some on hand for bad days, but that he did not need one every day.

Prostheses

To be defined as a prosthesis or prosthetic, a replacement limb must satisfy two major criteria. First it must be durable, made from a material that can withstand

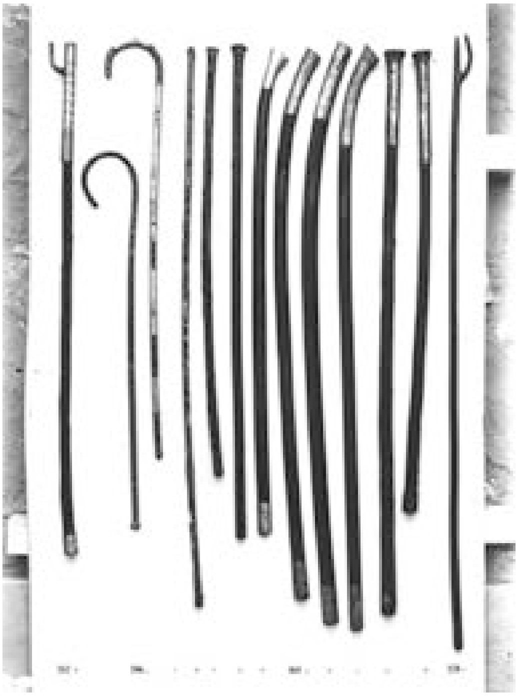


Fig. 7 An assortment of King Tut's sticks and staves. From the tomb of Tutankhamun (KV62). Grand Egyptian Museum, Cairo. (Photo: © H. Burton, Courtesy of the Griffith Institute Oxford)

Fig. 8 Stick 048b with a curved handle in the shape of a Nubian foe with his arms tied behind his back. From the tomb of Tutankhamun (KV62). Grand Egyptian Museum, Cairo. (Photo © A.J. Veldmeijer, E. Endenburg, courtesy of the Grand Egyptian Museum, Cairo)

bodily and external forces so that it does not snap or crack with use. Second, the device must be a functional and usable replacement for the missing limb, to the extent that the user can perform or even outperform all the tasks they would have used the limb for (Finch, 2011: 549). Because our purpose here is to investigate evidence for ancient assistive technology, rather than actually assess that technology, the term "prosthetic" will be used here to refer to any replacement limb regardless of effectiveness or appearance.

Although the term is modern, prostheses were – assuming Plutarch and Theodoros are to be trusted – enshrined in Egyptian mythology. As some versions of the story go, the vegetation god Osiris was vivisected by his brother Set and his body parts were scattered throughout the world. Isis, wife of Osiris and sister to both him and Set, went after them, recovering each piece and gradually reassembling him. She was unable to locate his penis, which was swallowed by a fish. Isis crafted a replacement and embalmed it with the other 16 pieces of Osiris to create the first mummy and resurrect him long enough to conceive his heir, Horus (Colazilli, 2012: 147). Since the replacement was fully functional – even if it needed the goddess of magic to make it so – we can consider it a prosthetic.

Prosthesis in Egypt took two forms: first, as in the mythical and modern sense, as a literal, functional replacement for a lost body part; and secondly, as an amulet or nonfunctional simulacrum intended to restore ritual wholeness (Colazilli, 2012: 148). Functional prostheses include toes and feet, while nonfunctional prostheses could be any sort of limb or body part. Finch and others suggest that prostheses of any sort are a natural outgrowth of the Egyptian belief that the physical body must be complete for the soul to progress to the afterlife. Embalmers had a well-documented practice of reaffirming body shapes with plaster, mud, sand, or extra linen, and stuffing sawdust beneath the skin to contour desiccated muscle and fill in empty eye sockets (Colazilli, 2012: 150). In this environment, replacement limbs are not a surprising development.

Functional Prostheses

What may be the earliest fully functional prosthetic device was reported from the Theban Necropolis in 2000. This prosthetic was an adducted hallux (big toe), found in situ still attached to its associated mummy (Nerlich et al., 2000: 2176). The mummy was identified as Tabaketenmut, the daughter of a priest who lived sometime between 950 and 710 BCE. Tabaketenmut may have had diabetes, which in turn caused the ischemic gangrene, resulting in the loss of the toe. She healed without stiches and apparently used this prosthetic toe to move around. Upon her death, it seems that it was embalmed with her so that her mummy would be complete (Nerlich et al., 2000: 2177).

The prosthetic itself was made in three sections: two of wood and third possibly of leather (Fig. 9). The main section was sculpted into the likeness of the missing toe, complete with articulated toenail, and with variation in texture on the ventral side that would aid in stability on the ground. A series of drilled holes supported a series of marlin hitches to secure the sections together. The pieces reveal that the carver (or designer) seemed to know anatomy and function of different parts of the foot (Finch, 2011: 549). Furthermore, the joints of the two wood sections seem to form an intentional hinge which mimics the flexion of the joints at the base of the toe. This suggests that the designers were knowledgeable of the mechanics of podiatric locomotion (Finch et al., 2012: 183).

Fig. 9 Prosthetic toe of Tabaketenmut, c. 950–710 BCE. From near Luxor. Grand Egyptian Museum, Cairo. (Photo: Finch et al. 2011, courtesy of the Egyptian Museum, Cairo)

A less complex prosthetic was acquired by the British Museum in 1881, now known as the Greville Chester great toe (Fig. 10). Its provenance is unclear but is probably also from Thebes. Scientific analyses in the late 1990s dated it to around 600 BCE, making it more recent than Tabaketenmut's toe (Finch et al., 2012: 182). The Greville Chester great toe is made from cartonnage, that is, linen soaked in animal glue and coated with plaster. It is also sculpted in the visual likeness of a big toe and once sported a false toenail. Holes on the medial signs show evidence of wear, possibly from laces, and plaster across the prosthetic shows evidence of wear in roughly the places a sandal would have been tied (Finch et al., 2012: 182).

Finch et al. constructed replicas of both the Greville Chester great toe and Tabaketenmut's toe for experimentation (Fig. 11). The replicas were tested with only two volunteers (finding volunteers with the correct pathology and no other health problems in the legs was noted to be particularly challenging), so the results were highly subjective (Finch et al., 2012: 184). Tabaketenmut's toe was deemed somewhat more effective than the Greville Chester great toe and wearing Egyptian-style sandals increased the effectiveness of both prostheses, despite the difficulties in having to keep both the prosthetic and the sandal in place. Finch et al. quip that the prostheses would be even more effective when encased in a sock and shoe (Finch et al., 2012: 189), neither of which the Egyptians are credited with inventing.

Nonfunctional Prostheses

Many prostheses were nonfunctional, and almost all of these are found with mummies to "complete" an incomplete body. Ritual wholeness was clearly very important and enshrined in mythology, for Osiris could not be resurrected without all his body parts accounted for or replaced. Rather than a simple instructional tale, the embalmers of Egypt seemed to take this story as a challenge: from the New Kingdom through to the Common Era, mummies were not simply prepared for the afterlife, they were gussied up for it. Embalmers stuffed sagging skin with sawdust, filled eye sockets with pebbles, applied makeup, buried the dead with reasonably fine wigs, and replaced any missing body part that should have been in the mummy and not a canopic jar (MacLeod & Cooney, 2019: 289).

Fig. 10 The so-called Greville Chester great toe. From Ancient Egypt (provenance unknown). British Museum, London. (Photo J. L. Finch 2012, courtesy of the Trustees of the British Museum)

Fig. 11 Experimental prostheses modeled after the prosthetic toe of Tabaketenmut and the Greville Chester great toe. (Photo © J. L. Finch 2012)

These replacement body parts range from tiny conventional amulets depicturing the missing body part to full size, yet still nonfunctional prostheses. They can usually be determined to be nonfunctional due to the lack of any features which would attach the prosthesis to the body during normal activity, or else were made of linen or similar nonfunctional material. For example, the Darlington Museum mummy, which dates to c. 250 BCE, appears to have been born without a left hand and forearm. A false hand and forearm were made of resin-soaked linen and fitted onto the stump. Clearly nonfunctional, the only use for this prosthetic was funereal (Colazilli, 2012: 151).

Mummy 1770 in the Manchester Museum had a linen penis and completely fake legs, the left one being a bundle of mud and reeds and the right one being wood (Fig. 12). The feet were made of mud, reed, and wooden pieces, and were adorned with painted slippers and gilded toenail covers. This extreme example probably lost his legs at the time of death, perhaps in an incident involving a large reptile or very large mammal. Interestingly, the wrappings date to around 380 BCE while the bones date to

Fig. 12 Prosthetic leg of mud and reeds. The Manchester Museum, Manchester UK. (Photo: Colazilli 2012, courtesy of The Manchester Museum, University of Manchester)

around 1000 BCE, suggesting that a Twenty-First-Dynasty mummy was refurbished in the Late Period (Colazilli, 2012: 151–153). That the linen penis is made of the same Late Period wrappings may indicate that the refurbishers were unsure of the mummy's sex, and therefore didn't commit to a plaster or stone replacement.

Another example is the mummy of Ankhefenmut, a priest from Thebes who lived during the Third Intermediate Period. The mummy now resides in the Albany Institute of History and Art. MRI scans undertaken in 2015 reveal the presence of a surprisingly dense false toe in the mummy (Fig. 13). Ankhefenmut's mummy has never been unwrapped, so the toe has not been examined physically, but the MRI reveals a crude piece of stone, roughly hewn into the general shape of a toe (Brier et al., 2015: 1047–1058). It seems, then, that this was a nonfunctional prosthetic as seen in the Darlington Museum mummy and Mummy 1770.

Another type of nonfunctional prosthetic is found in abundance. Amulets, it can be argued, are symbolic prostheses, particularly as they were used in Ancient Egypt. Embalmers who decided against faking limbs wrapped amulets in the shape of the missing limb into the wrappings, often close to their original location. Hands, arms, legs, and feet were the most common, but ears and noses have been found as well (Fig. 14).

But not all amulets can be considered prostheses. One amulet whose use as a prosthetic we cannot determine is the *wadjet* eye (Fig. 15). Recognizable and popular, *wadjet* eyes were symbols of protection and one of the most common tools of apotropaic magic in Ancient Egypt. As *wadjet* eyes were a common funerary amulet to include with the mummy anyway, there is little evidence that their presence indicates an injured or missing eye. Although they could logically have been appropriated for this purpose, eyes cannot be mummified and so eye injures can only be determined through osteological examination.

Another example of amuletic prostheses are golden tongues such as those found with the poorly preserved mummies at Alexandria's Taposiris Magna temple in February of 2021 (Fig. 15) and at Oxyrhynchus (El Bahnasa) in December the same year. These artifacts are interpreted to have been added to give the dead the ability to speak before Osiris, who since being mummied and fitted with his prosthesis, was now the god of death and rebirth (Davis-Marks, 2021). Such a

Fig. 13 Prosthetic toe of Ankhefenmut (MRI). From the Bab el-Gasus mummy cache. Albany Institute of History of Art, Albany, NY. (Photo © Brier et al. 2015)

Fig. 14 A wadjet eye amulet. From Ancient Egypt (provenance unknown). The Metropolitan Museum of Art, New York

practice is not suggested in early mortuary contexts elsewhere – at least, not in Egypt, where a symbolic "Opening of the Mouth" ceremony was performed to give the dead the ability to speak.

Fig. 15 A golden tongue from a mummy, Ptolemaic Period, c. 280–100. From Taposiris Magna. (Photo: © Egyptian Ministry of Tourism and Antiquities)

The closest antecedent to the golden tongues is the Hellenistic practice of placing a coin under the tongue of deceased person to pay for the soul's journey across the River Styx. Famously referred to as "Charon's obols," these coins could have been of any denomination, composition, and shape (Brown, 2008), and are attested in both archaeological and historical sources from across the Hellenistic and Roman worlds (Stevens, 1991). The Taposiris Magna and Oxyrhynchus tongues, therefore, could perhaps be seen as an appropriation and adaptation of the Hellenic practice for Egyptian religious beliefs.

Discussion

The fact that much of the material examined here comes from funerary contexts is arguably a clear example of preservation bias, since it is funerary contexts which make up the bulk of the surviving archaeological material in Egypt. However, this doesn't change the fact that the prostheses discussed above were deliberately placed in, or even made specifically for, this context. Why? Is ritual completeness enough of an explanation? Or is it something more? *The Book of the Dead* and its antecedents, the *Coffin Texts*, and the *Pyramid Texts* indicate that it is not simply a complete body that allows the deceased to make the perilous journey through the Duat – the underworld or the night world – to stand before Osiris (Faulkner and Allen 2005: 11–20). The dead needed access to the spells and directions in the funerary texts to make the journey, not simply a complete body.

It can be argued that upon death, Egyptian souls entered a disabled state. In order to progress on their journey, they need to be provided with accommodations in the form of funerary texts and assistive technology in the form of replacement or even supplemental body parts. Just as with modern accommodations and assistive technology, the prostheses, amulets, and spells leveled the playing field and allowed all souls with access to them to reach Osiris. As with modern accommodations, some individuals had greater access to assistive technology depending on their socioeconomic status. And as with modern accommodations, these measures ensured access, not success – the final judgement of the soul came at the iconic Weighing of the Heart, where only the deeds of an individual in life could secure an audience with Osiris and gain admission to Aaru – the afterlife.

At first glance, this argument seems exist in opposition to the interpretation suggested by the Egyptian artistic canon, which favors stylization and idealization. In this interpretation, the dead must be made perfect though the repair and refurbishment of the body, as well as the bestowal of the spells and directions necessary to traverse the Duat. However, stylization and idealization do not necessarily imply a spiritual desire for perfection, particularly since all periods of Egyptian art contain permissible exceptions to the rules of the canon, even outside the Amarna Period. Old and infirm people are portrayed in art, non-Egyptians living in Egypt are portrayed with realistic skin tones, women sometimes allowed themselves to be depicted with distinctive hairstyles, and dwarfs of high rank are portrayed with realistic relative height throughout all periods.

Disability is as much a sociocultural construct as a medical construct and is usually measured from difference or deviation from a perceived norm. Death is the ultimate deviation from the norm, and therefore the ultimate disability. If perfection were the goal, why wasn’t Tutankhamun outfitted with some prosthetic or amulet to rectify his clubfoot, rather than simply be buried with his walking sticks? Perfection was not the goal, immortality was. Metaphysically, the Duat is a liminal space between life and the afterlife, but it was also a space that rendered all deceased inherently disabled. While some were fortunate enough to only need the accommodation of funerary texts, others needed prostheses to make the journey forth by day.

Conclusion

Through this examination, we have seen that the ancient Egyptians crafted assistive technology far more complex than walking sticks, devising prostheses that would be deemed functional and effective today. It seems then that in Ancient Egypt impairment, regardless of whether it was considered disability, was indeed accommodated. In addition, this examination has revealed that the Egyptians were masters of a unique form of accommodation: assistive technology for the dead. This practice is a logical outgrowth of the Egyptians’ concern for spiritual completeness manifesting as a concern for physical completeness, as least as far as mummies are concerned.

What this examination does not reveal is how the Egyptians viewed individuals with impairments, i.e., the *shared social perception* of individuals which in our society is summed up in the word “disability.” Similarly, material evidence alone offers only a glimpse into the *lived experience* of these individuals who were accommodated with assistive technology but does not provide a complete picture. We do not know if average Egyptians perceived Tutankhamun as less of a king or less of a person because of his clubfoot. We do not know if Tabaketenmut, despite her effective prosthetic, still had so much trouble moving about the temples where her father worked that she had to alter her patterns of worship. Analysis of material remains is but the first step to reconstructing this shared social perception of individuals with disabilities, which is arguably the goal of the archaeology of disability itself.

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European Medieval Disability History: An Overview

8

Ninon Dubourg

Contents

Abstract

This chapter offers a targeted, macrolevel "need to know" overview of medieval disability scholarship and disability in the Middle Ages. History, art history, literature, and archaeology are all disciplines that count scholars working on issues linked to disability. The main argument I advance is that the common Christian culture operative in the Middle Ages supported the constitution of a pan-European identity, albeit with differences and nuances owing to local and national circumstances. In this context, disability was an intersectional node of identity that "sat beneath" the dominant identity category of Christian. We certainly encounter in the sources people with disabilities who faced numerous personal, daily challenges that sometimes impacted their ability to participate fully in medieval culture. Nevertheless, people with disabilities were not wholly excluded from their communities. In fact, people with disabilities were present in all spheres of medieval society, even playing leading roles, and thus were not inevitably marginalized. This chapter, then, aims to show that we find people with disabilities everywhere in the Middle Ages – if only we look for them.

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Introduction

Can we really speak of disability in terms of marginality when disabled people were present at every rank of society and when disability was not an insurmountable obstacle to social integration? This question cuts to the heart of core issues in the field of European medieval disability history and acts as an invitation to contextualize disability within a broader frame. The modern, popular imagination tends to frame disability in the medieval era as an overwhelmingly bleak fate, perhaps worse than death. Yet disability was not necessarily perceived, or experienced, as an obstacle to community life in the Middle Ages. Non-normative states could be, and were, accepted and appropriately managed by societal adjustments. Of course, the inclusion of disabled people within the social fabric varied according to the specific contexts in which individuals were embedded – their temporal, sociocultural, and geographical locations and more. Similarly, different kinds of historical sources offer different, even contradictory, representations of the experience of disability in the period. These fundamental ambiguities explain why medievalists working on disability history have, over the years, focused on a range of issues, using a diverse set of methodologies.

This chapter, in a nutshell, offers a targeted, macrolevel "need to know" overview of medieval disability scholarship and disability in the Middle Ages. History, art history, literature, and archaeology are all disciplines that count scholars working on issues linked to disability. The main argument I advance is that the common Christian culture operative in the Middle Ages supported the constitution of a pan-European identity, albeit with differences and nuances owing to local and national circumstances. In this context, disability was an intersectional node of identity that "sat beneath" the dominant identity category of Christian. We certainly encounter in the sources people with disabilities who faced numerous personal, daily challenges that sometimes impacted their ability to participate fully in medieval culture. Nevertheless, people with disabilities were not wholly excluded from their communities. In fact, people with disabilities were present in all spheres of medieval society, even playing leading roles, and thus were not inevitably marginalized. This chapter, then, aims to show that we find people with disabilities everywhere in the Middle Ages – if only we look for them.

Historical Context(s)

The Middle Ages begins in the fifth century, with the period's "birth" marked by important shifts in global sociopolitical contexts: the decline and fall of the Western Roman Empire and the concomitant Migration Period, the ascendency of the Byzantine Empire, and, in the seventh century, the rise of Islam. The medieval period comes to a close during the long fifteenth century, demarcated by the so-called Renaissance against the backdrop of the Black Death, the developments of the Reformation, the invention of the printing press, the voyages of Christopher Colombus, and the Ottoman Empire's conquest of Constantinople in 1453, which marked the end of the Byzantine Empire. The terms “Dark Ages,” “Middle Ages,” and “medieval” continue to be interrogated, and their analytical utility was debated, because of the way in which they obscure the historical specificity and richness of medieval societies and cultures and serve to situate derogatorily the time to which they refer: an uninteresting pause somewhere between glorious “antiquity” and magisterial “modernity” (Arnold 2008). Debate as to the validity of the term “Dark Ages” is ever ongoing (Falk, 2020; Fouracre, 2015) as in the 2016 Twitter debates “bring back the dark ages” (Williams, 2016). However, it is now very clear that the medieval period – which lasted for over a millennium! – is profoundly rich and undoubtedly complex (Aberth, 2018).

Since the aim of this chapter is to provide a succinct, and thus necessarily simplified, overview of medieval disability history, I will focus exclusively on Europe. Crucially, although Christianity was an essential common denominator, medieval Europe was not a homogenous territory by any means. The Western Roman Empire functionally ended in 476, with its power shifting to the East; Europe was the Empire’s heir, coalescing in the Early Middle Ages (Bartlett, 2015). Christianity began to take hold among the European elites, who in turn sought to Christianize their populations through assimilation and/or conquest with various timelines: some European regions were much slower to adopt the religion than others. From the twelfth to the fourteenth century, Christianity was dominant in medieval Europe and reached its peak in terms of its geographic spread and the size of its pan-continental congregation (Bend, 2006). This chapter concentrates on the thirteenth and fourteenth centuries, i.e., the latter period of the Middle Ages. This is less of a deliberate choice than a scholarly necessity: there is a dearth of research on disability in the earlier part of the era, though this gap is slowly being filled (Jones, 2012; Skinner, 2017).

While it is possible, even necessary, to offer generalizations about medieval Europe, the principles upon which such generalizations depend are not universal and do not allow us to capture authentically the full complexity of medieval societies. For this reason, then, this chapter does not claim to cover all the spaces or periods of the Middle Ages, nor does it proffer any fixed, final “answers.” Rather, it provides an overview of disability in the Middle Ages and discusses some of the main questions that are being posed by medievalists about disability history, showcasing the latest research in the field.

Critical Context(s)

Historical work from medievalists prior to the 1970s tended to situate disabled people primarily as a sub-grouping of the poor, focusing on the analysis of hospitals, charity, poverty, infirmity, and/or assistance. Effectively, medievalists replicated an understanding of disability in terms of exclusion prevalent in their societies and applied it to premodern society (Haggard, 1932). These studies were especially prominent in French historiography (Geremek, 1980; Goglin, 1976; Mollat, 1978). The medical model upon which medievalists previously depended has, however, been roundly critiqued. Henri-Jacques Stiker pioneered the implementation of this kind of critical approach in a historical context with the publication of his seminal book *Corps infirmes et sociétés* (A History of Disability) in 1982 (Stiker 1982, 2009 in English). Stiker encouraged the production of a history of the representation of disabled people. He sought to understand the viewpoint of premodern individuals living with physical or mental incapacity, interrogating specifically medieval sources relating to beggars in the archives of now-defunct hospitals. The studies of medieval disability that followed tended to take legislative documents as a starting point for analyses, such as those related to the receipt of charity (Adam, 1982; Agrimi & Crisciani, 1980).

Researchers gradually began to expand their focus, considering disability mostly, if not exclusively, in terms of social exclusion by interrogating the social *inclusion* of disabled people. This development tied directly into political activism and the desire to significantly improve the lives of disabled people and gain more civil rights (Trexler, 1985). Hence, in the 1980s and thereafter, the articulation of the "cultural model" of disability, as a part of the broader "linguistic turn," initiated in the 1970s and 1980s by academics studying the intersections of culture, language, and discourse (Hughes, 2002). This model considers that a phenomenon such as disability is not limited to material conditions (i.e., social model), and, as such, disability is not a fixed category of experience. On the contrary, what is experienced and understood as disability changes according to the specifics of the period and culture in question (Snyder and Mitchell 2006). Medieval historians have, accordingly, excavated a cultural history of disability in the Middle Ages, interrogating how medieval society produced the disabled body by establishing norms from which it "diverges" (Campbell et al., 1992; Eyler, 2010; Fandrey, 1990). In this work, medievalists also frequently rely on the "minority-group model" of disability, a framework developed in the human sciences which supposes that disabled people belong either to a stigmatized group or to a subculture. This thesis, which stems from American multiculturalism, supposes that people with disabilities form cultural groups, because disability produces a particular identity, relative to normative "common" experiences of able-bodiedness (Hedlund, 2009). The Deaf Community is most often referred to in the literature as an example, given the existence of a common language and a cohesive, non-dominant culture (Brueggemann, 2005). Many, if not most, publications in this generation of research are segmented studies with a singular focus, bracketing off conditions according to the type of disability, with much attention paid to old age (Rosenthal, 1996; Shahar, 1997), blindness (Weygand, 2003), and mental illness (Katajala-Peltomaa & Niiranen, 2014; Metzler, 2016; Turner, 2010, 2013). Similarly, research in this mode is often organized according to a taxonomy of care, in terms of the institutional arrangements put in place to care for disabled individuals, support structures which differ according to the nature of disability. This is evidenced by the numerous research studies on leprosy and leprosaria (Brody, 1974; Ephraim, 2014; Touati, 1998).

Scholarship in the field of medieval disability history came into its own in the mid-2010s, with a marked increase in publications after 2005. At the same time, the "critical model" of disability emerged, created to synthesize the best that the social and cultural models have to offer. This analytical schema proposes a comprehensive approach to disability and infirmity as cultural phenomena. Researchers using this approach question power relations, seeking to shed light on the sociohistorical conditions of oppression that are geographically specific (Meekosha & Shuttleworth, 2009). However, unlike the cultural model, it is no longer sufficient to add the most marginalized categories to the syllabus, but they must be taken into account in order to change our understanding of society as a whole (Shildrick, 2012). In the field of colonial, postcolonial, or neo-colonial disability studies, the variation of the viewpoint is as much in space as in time (Sherry, 2007). Faced with these similar objects, many historians are inspired by the spatial approach to enrich their problems.

Medievalists have profited from the latest developments in the field of critical disability studies, publishing major synthetic studies that attempt to write the history of people with disabilities in medieval times (Metzler, 2006). However, by and large, such work is collective and collaborative, while book-length studies remain rare (Hsy et al., 2020). This reflects the novelty of this critical approach, and its limited application in historical disability studies (Collard & Samama, 2010; Nolte, 2009). Despite the fact that few historical publications currently adopt this interdisciplinary way of thinking – with disability interrogated as one of many intersecting components of identity in medieval society – the field is all but united in calling for the implementation of this kind of innovative methodology (Barschet et al. 2013; Turner & Butler, 2014; Krötzl et al., 2015; Turner & Lee, 2018). Medieval disability continues to develop as a field, with ever more publications analyzing ever more (kinds of) medieval sources (McNabb, 2020; Turner & Pearman, 2010)· Consequently, the most recent works use disability as a category of analysis that obliges us to rethink the principles of medieval society that have long been taken as fundamental and, in so doing, to engage with, even change the way we think about contemporary disability (Godden & Hsy, 2013; Waldschmidt, 2010).

With this in mind, I begin with a discussion of general representations of disability, drawn from the imaginary of medieval elites in which disabled people are conceived of as beggars. This portrayal, which served to maintain social hierarchies, provides the stereotypical image of disability in the Middle Ages, one that still prevailed in the literature until about a decade ago, in which disabled people are thought to be entirely excluded from the normative social fabric. The following section provides a more holistic picture and demonstrates that this contention offers only part of the story: disabled people were certainly subject to social exclusion in substantive ways yet were also able to participate dynamically in their society. In the third section, I rely on material from literary texts and miracle testimonies which give insight into the lived experience(s) of medieval disability and the possibility of maintaining high social status as a disabled individual. In this way, the focus of analysis is narrowed from the generalized, macrolevel to the microlevel of personal, quasi-biographic accounts of disability in the Middle Ages.

I. Disability, Poverty, and Charity

In the medieval public imagination, the *imago Christi* (the image of Christ) ruled as the stereotypical portrayal of disability. Disabled people were routinely depicted as vectors of salvation for the richest Christians, either in receipt of alms which demonstrated the piety of wealthy benefactors and for which recipients may “pay” with prayers on donors’ behalf or subject to miraculous healing which showed the glory of God Himself. In numerous ecclesiastical sources, the scribe and/or the illuminator chose to depict “cripples” as poor beggars, living off alms. As such, it seems that medieval disabled people relied for their survival, ideologically and literally, on an established system of charity, a transactional practice in which their role was primarily to offer spiritual “resources” to their able-bodied betters. These documents represent and reproduce perspectives from the top of the social hierarchy, the attitudes of the elite, for whom charitable donations to the disabled were not simply magnanimous. Rather, engaging in charitable acts by donating alms to disabled people served to reinforce the elite benefactors’ elevated social role, further ossifying the social hierarchy. This dynamic is witnessed in numerous medieval texts and pictures, as discussed below.

Before engaging in such analysis, however, it is crucial to understand the context in which such depictions operate. Medieval poverty is not the poverty we know today. Indeed, poverty in the Middle Ages has perhaps a broader meaning than today: the poor lacked the physical means to ensure their own subsistence and lived on the margins of society as its most vulnerable, low-status members. Nevertheless, they were endowed with a specific social role. In addition, “the poor” (*impotens* or *debilis*), as a category, traditionally comprised a wide swathe of people that included the elderly, infirm, sick, orphans, children, widows, and pregnant women. Irina Metzler examines the link between poverty and disability through the prism of charity in her landmark 2013 book (Metzler, 2013).

Metzler advocates that from the Merovingian period onward, bishops, abbots, and towns identified poor people with numbers in order to keep track of them. Long lists of precise criteria, preserved in legal sources, were utilized to “correctly” classify these poor citizens (Meier, 2005). This meticulous system facilitated the recording of individuals who were authorized to beg, alongside membership rolls of brotherhoods or guilds of beggars, groups that sometimes gathered a type of disabled people (leprous, blind, etc.). Such records were used by bishoprics and monasteries to verify which poor people were entitled to receive donations from Christians. In exchange, alms’ recipients had to save their rich donors’ souls through prayer. The charitable system was organized from the top down, with authority granted to rich donors, monastic communities, and bishoprics. These privileged groups decided what form and function their local hospitals should take, according to their personal aspirations, family ties, and/or the needs of their community (Sweetinburgh, 2004). The foundation of such charitable institutions demonstrated the eminent social status of those in charge; the larger the premises, the greater the number of poor people accepted within its walls, or the relative severity of the poor inhabitants’ needs, the more illustrious the benefactors appeared (Rubin, 2002).

Hospitals were part of the ecclesiastical infrastructure from the beginning of the medieval era. The figure of the bishop was central in their formation and running, as caring for the poor was absolutely fundamental to his role. Initially, hospitals were not (solely) medical institutions. They provided accommodation and food to the poor, operating as community hubs in which individuals' access to charity was determined, and alms were distributed to the "verifiably" needy (Lazard, 2001). For this reason, then, illness and poverty are confused in records relating to charitable assistance between the seventh and ninth centuries. From the ninth to the eleventh centuries, the generic term "pilgrim" is used in texts to refer to all those who received therapeutic treatment from monks (Montford, 2004; Yearl, 2007). The introduction of secular charity in the thirteenth century led to the gradual secularization of such institutions (Rawcliffe, 1995). This shift also led to institutional specialization, with a given hospital specializing in a specific type of infirmity, according to the funders' preference (Brodman, 2003). Consequently, charitable institutions incrementally acquired an explicitly medical function, transforming them into hospitals more closer to the modern sense of the term (Dumas, 2015). This suggests improved treatment for the poor, at least in medical terms. In the same time, cities and kingdoms began to regulate their poor citizenry as early as the thirteenth century. Restrictions on begging were introduced, ranging from increased scrutiny – mandatory examinations of beggars, the obligation for beggars to carry distinctive signs – to strict controls. In some cases, begging was functionally eliminated by the expulsion of anyone without employment from the city. The definition of the term "poor" narrowed and was now applicable only to individuals without the capacity to work and thereby support themselves. This prefigures, as Metzler notes, modern disability legislation that recognizes a person's disability in similar terms, based on their capacity.

To return to disabled people and/as the *imago Christi*, Livio Pestilli notes that disabled people were routinely depicted in two configurations in the Middle Ages: as petitioners for miraculous healing and as recipients of alms (Pestilli, 2016). The first representations of disabled people in manuscripts occur in the context of hagiography, books of saints' lives, in which they figure as prospective beneficiaries of saints' salvific cures. In their earliest form, such scenes were depicted in miniatures, though they are also found in margins during the thirteenth and fourteenth centuries. This amounts to an integration of disabled people in manuscript culture, which, as Pestilli points out, reflects the growing importance of the Christian precept of charity as part of the Gregorian Reform. Representations of disability which foreground charity serve as a mechanism for modeling laudable Christian behavior. At the same time, noble patrons instrumentalized manuscript illumination to enhance their own social and political prestige: by highlighting the importance of charity in such images, they drew attention to their own piety, as donors themselves, beyond the manuscripts' borders.

The *infirmi* (impaired people) played an important social role in the system of Christian charity. They were the archetypical poor, the best – the neediest and thus most worthy – recipient of alms. For this reason, they were mainly depicted as beggars in narrative vignettes contained in manuscripts. Such representations served to glorify the act of charity itself and, in so doing, functioned to maintain social hierarchy, the power imbalances between men and women, rich and poor. These manuscripts necessarily offer a skewed perspective, as they were made for the richest Christians. Nevertheless, the donation of alms is an oft-repeated subject in all kinds of texts and images, cropping up as a reminder to donate to the poor, or as a means to memorialize and celebrate past gifts. This is the case, for instance, in a marginal scene in the *Smithfield Decretals* (Fig. 1), an edition of Gregory IX's book of canon law that was illuminated in London during the mid-thirteenth century for an unknown owner (Taylor, 1996). This image offers a tableau of four individuals and portrays the interaction between rich charitable donors and the disabled recipients of their alms.

The two figures to the left of the scene are depicted with their hands held out, a visual indicator of begging. One sits on the floor with crutches placed nearby, suggesting a mobility impairment such as paralysis. The other figure is standing, appearing to limp toward the pair of figures to his right. While the limping figure is half-naked, the two individuals with whom he engages are richly decked out, one even wears a crown and seemingly has clothes to spare. The king proffers a coat and some cash to the two beggars, as his escort clutches the royal purse. This implicitly references the legend in which St Martin of Tours gives his coat to a beggar. The latter was sometimes figured in ecclesiastical images as able-bodied, though others depicted him a disabled (usually as a foot amputee). Then, this is an archetypical depiction of an act of charity and thus was likely immediately recognizable to contemporary viewers. The scene's players are unambiguously situated as the top and bottom of the social hierarchy: the donor is a king, the richest of the rich; the poor are disabled. Disabled people are fairly often represented in such images with crutches or similar assistive objects, signaling some form of paralysis or mobility impairment. Similarly, the king is identified as such by his crown, another visual marker that the artist used to distinguish their subject(s) from "normal" people (Godden, 2016). Clutches and other assistive devices allow for the depicted figures to be identified *as disabled*, thereby offering us insight into the variety of prostheses used by disabled people during the Middle Ages. What's more, the use of visual markers to denote disability serves to group disabled people together; they share the same symbolic attributes as markers of their distinct, shared social status, alongside their similar symbolic value within society. While disability is frequently depicted in

Fig. 1 London, British Library, Royal MS 10 E IV, f. 262: King offers coat and coins to a disabled beggar. (Copyright © CC-BY-NC 4.0)

terms of *imago Christi*, as in Fig. 1, the fact that disabled people figure in manuscript illumination so often ultimately shows the extent to which they were integrated within society more generally.

II. Ambivalence: Salvation and Sin, Inclusion and Exclusion

Disabled people in the Middle Ages were met with ambivalence. On the one hand, the transactional spiritual economy, as expressed in the system of Christian charity, depended upon disabled people as vectors of salvation, with care for the disabled a core component of what it meant to be a good Christian. At the same time, disabled people might be isolated, maybe ostracized by the able-bodied community, especially if they lived with leprosy. Like today, people with disabilities in the Middle Ages were subject to mockery, notably because they inverted expected standards. Attitudes toward disabled people, and the signification of disability itself, were equivocal. Disability could be a divine punishment for an individual's evil or their parents' immorality and could thus denote innate sinfulness. But disability, understood as a divine burden, could bring an individual closer to God and salvation: disabled people could be models of holiness.

Medieval society tended to physically group disabled people together in order to facilitate care, individually and/or collectively – much as is the case today. Receiving care necessitated social exclusion to some extent. Indeed, archaeological evidence testifies to cases of "care exclusion" in medieval communities. Frédérique Blaizot's study of 24 burials in the funerary complex of Beaume in Châteauneuf-sur-Isère (Drôme, France) is highly illustrative (Blaizot, 2009). These tombs, located at some distance from religious buildings, belonged to individuals with disabilities resulting from serious accidents, or illnesses related to their old age. The archaeological evidence establishes that these people were unable to take care of themselves and required daily care. Blaizot shows that the disabled people in these plots were buried according to standard funerary practices but, critically, that their tombs were placed outside the parish cemetery, the usual resting place for the area's deceased. The specificity of this burial site reveals some kind of exclusion to which the disabled were subject in their life as in their death. However, Beaume, a small hamlet, appears to have cared for its disabled populace with an arrangement based on community care, something akin to a retirement home, with residents technically sheltered within the community yet simultaneously separated, as a group, from its other inhabitants.

This dynamic of relative exclusion, linked to the specificity of care required, is even more prominent in cases of leprosy, and the institutions that were established to house and care for lepers. Leprosy is a progressive chronic disease that affects the peripheral nervous system, skin, and/or nasal mucous membranes, causing loss of sensation in the limbs, which can lead to amputation. In the Middle Ages, leprosy was incurable and thus might have provoked fear in the healthy population. The condition was also strongly associated with sin in some texts, like the sermons (Bériou & Touati, 1991). In the latter, the disease's effects of physical degradation were understood to be a reflection of the leper's moral corruption, with lepers subject to cruelty, ridicule, and social ostracism – but also as a test for the righteous. For such reasons, historians have long believed that lepers were almost entirely excluded from medieval society (Tabuteau, 2007). Research on the condition has traditionally focused on leper hospitals (*leprosaria*), monastic-like institutions in which lepers were typically cloistered, with such exclusion long explained by historians as a public health measure (Rawcliffe, 2006). Recent scholarship, however, challenges this notion, highlighting the fact that lepers in such institutions were living in new forms of community life and were not cut off from the world; *leprosaria* were part of the urban or rural fabric.

Elma Brenner's, 2015 monograph offers an interesting case study of leper houses in the French city of Rouen during the twelfth and thirteenth centuries (Brenner, 2015). Analyzing archival materials, Brenner demonstrates the way in which the link between leprosy, charity, and practices of piety enabled, even demanded, the inclusion of lepers in the diverse social fabric of medieval Rouen. The people who lived in Rouen's leper houses were considered to be patients, not inmates. The leprosarium, as an institution, permitted their social inclusion by remaining within their local community; as recipients of charity, lepers were integrated into Christian society. Some of Rouen's lepers – a group comprising both men and women, clerics and laypeople – were resident in the Augustinian priory of Mont-aux-Malades. Situated in a prestigious locale, at the entrance of the city, they received healthy visitors and participated in the city's life, for example, by organizing an annual fair. More generally, Rouen's lepers were the recipients of charity not just from the city's bourgeois but also from nobility and royalty. The king of England Henry II, for example, founded a community for women lepers in the twelfth century. Such donations allowed the leprosarium to amass significant economic assets, endowing its residents with considerable financial means. The situation was not equally favorable for all lepers, however. Brenner shows that lepers without the financial reserves to join a leprosarium remained marginalized in the community. Poor lepers in Rouen were, for example, compelled to beg, even in front of the gates of the cathedral. In sum, there are no clear-cut answers in the debate about the relative inclusion or exclusion of lepers in medieval society. Findings depend upon the specific context(s) under investigation and vary from segregation to integration (Dubourg, 2018; Spencer-Hall, 2015). Nevertheless, the latest research tends to highlight the ways in which lepers were valuable members of the medieval society, sketching the range of roles they could and did occupy (Brenner & Touati, 2020; Orlemanski, 2012)˙

Notwithstanding their relative social inclusion, disabled people, as personifications of the inversion of expected standards, were routinely subjected to cruel and ruthless ridicule. Such "timeless" mockery of disabled people – present even today – circulated in medieval texts and images and cannot be ignored. Perhaps the most famous, or at least the most studied, comic depiction of disability is found in the so-called "blind beating the pig" game (Richard, 2015). First documented in the thirteenth century, the "game" proved popular and was still being played at the end of the fifteenth century in at least 11 towns. The notionally sporting event consisted of a quasi-gladiatorial match between blind beggars and a pig, with the beggars earning the right to eat their porcine foe if they beat it to death with a cudgel. The entertainment factor lay in the likely eventuality of the beggars hitting each other, rather than their quarry. A painted miniature (Fig. 2) in a Flemish manuscript of the *Romance of Alexander*, illuminated by Jehan de Grise in 1338–1344, offers a snapshot of a typical match.

On the left, a little boy leads four blind beggars, equipped with sticks, into an arena; on the right, one beggar clubs his compatriot over the head, tripping over an unfussed pig, while the third beggar appears to be about to do the same to another unfortunate friend. Mocking depictions of disability were not only intended to generate laughter but also offered powerful moments of catharsis. Both were generated by the inversion of norms embodied by disabled people (Thomson, 1996). Richard asserts, for instance, that laughing at (the fear of) blindness and poverty helped medieval townspeople to accept disabled people in the urban context. The inclusion of blind beggars as "knights" in tournaments for comic effect, such as the "blind beating the pig" "game," functioned, ultimately, to improve the social inclusion of disabled people more generally. Comedic and parodic representations of disability also served constructive pious and didactic purposes, reminding audiences of the importance of engaging in charity, for example (Gurevitch 1990). Consideration of this aesthetic corpus allows us to better understand the conceptualization of marginality and alterity in the medieval imaginary (or at least the imaginary of artists and their rich clientele), including the ways in which normate subjects structured their own identity in relation to those deemed "other."

III. Integration of Disabled People Within the Social Fabric

While disabled people were subject to mockery in the Middle Ages, that did not preclude their broader social integration. Tantalizing glimpses of the diverse experiences of disability in the era are found in depictions of disabled people in the

Fig. 2 Oxford, Bodleian Library, Bodl. MS 264, f. 74v: Blind people hitting each other with sticks ("blind beating the pig" game). (Copyright © CC-BY-NC 4.0)

context of other facets of their intersectional identities. In manuscript's margins, a relatively limited, yet highly connotative, corpus of images, we find not just disabled beggars but disabled peasants, townspeople, prominent citizens, and even knights. The images provide an invaluable source to understand how disabled people navigated the sociocultural, physical, and mental effects of their conditions, especially in terms of strategies used to maintain their social status after the onset of disability. A miniature from the fourteenth-century *Romance of Alexander* (see Fig. 3) that shows how a servant could help their master manage a mobility impairment is again illustrative.

To the left of the image, a crowned figure reclines on a cart, pushed by his servant to the right of the frame. The king, pictured with only one leg, appears to be a lower-limb amputee, probably as the result of a war injury, as he is still dressed like a knight. The image testifies to the availability of assistive devices, and the usage thereof, by disabled people in the Middle Ages – or at least by members of the rich elite, like the pictured king.

The pervasive ambivalence toward disability in the Middle Ages cannot be ignored, however. This is especially the case in terms of the religious binary which oriented attitudes to disability: disability was either a sign of sin or of holiness, with reactions oscillating between compassion and rejection (Scarborough, 2018). The moral model posits a direct link between personal and/or parental fault and an individual's physical or mental disability, an interpretation that has been in circulation since antiquity (Breitwieser, 2012; Kristiansen et al., 2009). Physical or mental "imperfection" signifies a lack of virtue and is effectively a highly targeted "plague" wrought by a moral defect operative either in the disabled individual themselves or their progenitors (Gianfalla, 2010). By contrast, another model offered a more positive view of infirmity: disability was understood as a spiritual opportunity, a test initiated by God to enable the individual to prove their faith (Cusack, 1997).

Fig. 3 Oxford, Bodleian Library, Bodl. MS 264, f. 158v: Disabled king in cart, pushed by a servant. (Copyright © CC-BY-NC 4.0)

Pious Christians should endure all the calamities that the Creator sends them without questioning his goodness. This explains the relatively high incidence of disability in stories of saints and holy men and women. While the connection between disability and holiness could certainly be affirmative, disabled saints were largely defined in relation to their body, with their disability a core aspect of their sanctity (Kuuliala, 2020). In effect, disabled saints were often reduced to their disability alone, with little attention paid to their subjecthood.

Conflicting attitudes toward disability were not mutually exclusive nor entirely fixed: different sources offer different, even contradictory, perspectives on the topic. The moral model foregrounds medieval society as fundamentally exclusionary, with disability stigmatized on theological grounds. Yet its counterpart, the "spiritual-opportunity" model, emphasizes that the challenges posed by disability can be a route to holiness, on the proviso that such difficulties are met with gracious forbearance. Inclusion of difference is presented as an important tenet of a truly pious medieval Christian society (Frohne and Horn 2013). In the end, such ambiguous conceptualizations reveal how prevalent disabled people were in medieval society, with their disability ascribed various significations and instrumentalized for a range of purposes. This is the case, for example, in the leveraging of disability for "narrative prosthesis," a phenomenon evident in many medieval texts, literary and otherwise (Bearden, 2019).

With the term "narrative prosthesis," David Mitchell and Sharon Snyder theorize the ways in which disability is conjured in a given text as a means to propel the narrative forward, triggering the intervention of characters in order to "fix," and thus erase, the disability at hand (Mitchell & Snyder, 2000). Tory Vandeventer Pearman, for example, analyzes the social category of knighthood in terms of its complex internal dynamics (Pearman, 2018). Knighthood rests upon the physical and mental capacity to fulfill chivalric functions, including fighting, military strategizing, and courtly etiquette. Yet the role bears with it a high risk of acquiring disability, through injury. Indeed, as Pearman demonstrates in a close reading of Sir Thomas Malory's *Morte d'Arthur*, a knight is *supposed* to suffer from bodily and mental injuries to prove his valor in combat and, subsequently, to reinforce his chivalric reputation. Contrary to what one might first think, disability did not always prevent knights' participation in battle, as various studies have shown (Metzler, 2013, Chap. 2). Rather, injuries functioned as tangible, bodily proof of a warrior's chivalric prestige and his associated social worth. Malory's knights are, thus, trapped in an endless cycle, healing from battlefield injuries only to return to combat, risking new harms from which they will seek to heal, starting the process anew. In so doing, they seek to heal not only their physical body but also the social body of chivalry itself, paradoxically achieved through battlefield wounds which demonstrate the prestige of knighthood. In this way, disability is utilized in the *Morte d'Arthur* in a mode of "narrative prosthesis," an essential artifact which catalyzes narrative progression, constantly (at threat of) being erased. Pearman also wrote on how "womanhood" and "disability" function in the same way to shape literary texts (Pearman, 2010).

"Narrative prosthesis," as a trope, is perhaps most pervasive in another genre of medieval literature: miracle collections (Spencer-Hall, 2020). These anthologies, collated for canonization trials, present tales of saints miraculously healing all manner of disabilities. Disability in these texts is emphatically a problem to which a solution is sought. Jenni Kuuliala, a pioneer in this area, analyzes testimonies offered in thirteenth- and fourteenth-century miracle collections to uncover the everyday experiences of disabled people which subtend the dominant discourse (Kuuliala, 2016). She notes that, unsurprisingly, individuals had to grapple with significant consequences linked to disability in their daily lives, and the social expectations to which they were subject, if their condition were congenital or if acquired before the age of 14. In other words, disability acquired later in life, when an individual's social status and identity were already established, was understood, and experienced, differently.

Kuuliala deconstructs the "narrative prosthesis" at play in the miracle tales by pinpointing their integral partiality. These accounts are necessarily biased by the hagiographic context in which they appear, not to mention the heightened emotionality of the curative interlude, and, often, the long gap between the date of the cure and its recounting for the canonization process itself. Interviewers seeking persuasive miracle stories for the saint's dossier used pro forma questionnaires to elicit desired responses; witnesses' answers were often summarized or translated from the vernacular into Latin. In other words, miracle collections' treatment of disability is impacted by the sources' demonstrable aims, including verifying the saints' holiness via spiritually impressive healings. The erasure of disability was not a simple "fact" of medieval culture. Kuuliala's work opens up new perspectives on the attitudes of communities and families toward disabled people in premodern times by highlighting the strong bonds of kinship, affection, and solidarity that anchored disabled people in their sociocultural contexts.

Pearman and Kuuliala's scholarship, and the issues raised therein, emblematizes a new wave of research on medieval disability. This research provides concrete evidence of the social integration of disabled people, not just in the elite social sphere but in all kinds of communities, families, and circles of affinity.

Conclusion

Medieval representations of disabled people reflect the integral diversity of experiences of disability in the Middle Ages, as today. They also highlight the complex signification(s)s ascribed to disability in the era. The frequency with which disabled people appear in all kinds of medieval sources reveals their broad social inclusion, even when portrayals of disability are negative, even cruel. Medieval people grappled with what disability meant and how it impacted lives – just as we do in the twenty-first century. The challenges we face today often resemble those faced by our ancestors. Similarly, disabled people across time were not reducible to their disability alone. They could be empowered in various ways and lead rich lives.

Medieval media incorporated, even foregrounded, disabled bodies in all kinds of works, visual, literary, architectural, and more. It is essential to acknowledge, however, that the medieval representations to which we have access are marked by the worldview of their creators and their privileged consumers. As such, they can only offer a partial, at best, view of the lived reality of some disabled people. Nevertheless, these sources transmit the attitudes of a range of cultural taste-makers – patrons, planners, artists, craftspeople, authors, notaries, scribes, and, to some extent, readers and viewers – toward disability. Close attention to a wide range of sources allows us to perceive the structural ambivalence in which disability, as a concept, was embedded. Disabled people were not solely catalysts of Christian devotion and/or subjects of mockery or fear but were also potent symbols of diversity in the medieval world. The disabled body signified sin, but it also embodied Christian ideals of charity, acceptance of one's divine lot, a path to salvation. Disability invited ridicule but also care, assistance, and solidarity from loved ones and the community. Disabled people experienced life in the shifting borderlands between (partial) exclusion and social integration. As in the twenty-first century, the experience of disability in the Middle Ages was anything but uniform.

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Disability in US History

9

Caroline Lieffers

Contents

Abstract

People with diverse bodies and minds have existed since the origins of human habitation in what is now the United States, but how that diversity has been understood has changed dramatically over time and across cultures. This chapter begins by surveying experiences and understandings of disability in Indigenous communities and colonial America, emphasizing how different cultures made sense of human variation in dramatically different ways. Indigenous peoples often interpreted bodies and minds through individuals' relationships with the larger community and the spiritual world, while early settlers established legal structures that sought ostensibly to protect but also effectively marginalized certain classes of people. This chapter then moves to examine disability's intersections with race and slavery, as well as the power and influence of industrial capitalism and medical authority. Attitudes toward disability shaped and were shaped by other forms of discrimination, as well as concerns about economic expediency, and medical experts and the state were increasingly inclined to intervene in the lives of people with disabilities in the late nineteenth and early twentieth centuries. But disability, importantly, has also been reconstituted and redefined through disabled people's efforts to claim what they have been denied or to build

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alternative communities and futures for themselves, asserting rights and resisting ableism. Disability history is a powerful tool for illuminating structures and discourses of power, identity, and discrimination in US history writ large, and its ability to demonstrate contingency and change over time helpfully de-essentializes understandings of how people experience differences of mind, body, or senses.

Introduction

People with diverse bodies and minds have existed since the origins of human habitation in what is now the United States, but how that diversity has been understood has changed dramatically over time and across cultures. Over the past several decades, historians of American disability have done remarkable work in responding to Douglas Baynton's now famous comment that "[d]isability is everywhere in history, once you begin looking for it, but conspicuously absent in the histories we write" (2001, p. 52). Baynton reminded readers not only that "disabled people have a history, and a history worth studying" (p. 52) but also that concepts and categories of disability are socially and culturally mediated.

Scholars have examined numerous dimensions of disability in US history, considering the experiences of people with variations of mind, body, or senses, as well as the understandings of disability, ability, and capacity that have shaped their lives and American culture more broadly. In many cases, these understandings intersected with and even helped to define or reinforce other social and cultural dimensions and categories, including race, ethnicity, sexuality, gender, class, and stage of life. Disability history is thus a powerful tool for illuminating structures and discourses of power, identity, and discrimination in US history writ large, and its ability to demonstrate contingency and change over time helpfully de-essentializes understandings of how people experience differences of mind, body, or senses.

Central topics for US disability historians include the histories of institutions and institutionalization, war injuries, societal expectations of labor and laboring bodies, attempts to govern reproduction, and immigration restrictions, as well as identity and community formation, activism, and the struggle for disability rights. Across all of this diverse work, however, a key matter comes consistently to the forefront: categories and experiences of disability were frequently shaped by ableist exclusion that put certain people at – or entirely outside – the boundaries of citizenship and social and cultural belonging. To be sure, people with diverse minds, bodies, and senses have always existed in US history, and some found shared identities on the basis of similar characteristics or experiences. But disability's coherence and significance as an analytical category arguably emerge most clearly through attention to how this diversity was met with various forms of discrimination, including the denial of mobility, social participation and belonging, and the rights and privileges of liberal citizenship. Moreover, the denial of full inclusion and rights to people who either have disabilities or are perceived as disabled has often worked in close conjunction with efforts to enforce other norms, expectations, and prejudices, whether religious, economic, or racial (to name just a few). Disability is thus deeply political and inextricable from other vectors of marginalization.

This chapter examines these processes at work. It begins by surveying experiences and understandings of disability in Indigenous communities and colonial America, emphasizing how different cultures made sense of human variation in dramatically different ways. It then moves to interrogate disability's intersections with race and slavery, as well as the power and influence of industrial capitalism and medical authority. But disability, importantly, has also been reconstituted and redefined through disabled people's efforts to claim what they have been denied or to build alternative communities and futures for themselves, and this chapter ends with attention to these efforts to assert rights and resist ableism. Disability's ragged edges and shifting applications and definitions over time testify to its position at the intersection between human difference and the operation of political and social power.

Indigenous Cultures and Colonial America

Though it is often inappropriate to generalize across Indigenous cultures in North America, scholars have noted that many Indigenous communities in what is now the United States were characterized by systems of social belonging that did not exclude people with disabilities. While people certainly experienced injury, frailty, and sensory or cognitive differences, for example, they continued to participate fully in the life of their communities, share wisdom and experience, and maintain strong relationships. The Umo^{n}ho^{n} (Omaha) Nation in what is now Nebraska, for instance, took human difference and need as matters of course. When a child reached the age of 3 or 4 and could go in whatever direction they pleased, they would undergo the ceremony of "turning the child," indicating that they were ready to be recognized as an individual and inducted fully into the community. But the ceremony also included an acknowledgement of the day when they would reach old age and "be bowed over" (Fletcher & La Flesche, 1911, p. 118). Independence and dependence wove in and out of one another.

Among the Umo^{n}ho^{n}, weak or sick people also played an integral role in the body politic. Washna, a tender part of the buffalo intestine, for example, was reserved for old people who had but few teeth; young people learned that if they ate it for themselves, dogs would bark at them during their hunting excursions (Fletcher & La Flesche, 1911). Similarly, those who were too elderly or infirm to participate in the annual hunts, which could last for weeks or months, were known as he'begthi^{n}, "those who sit half-way" (Fletcher & La Flesche, 1911, p. 99). They were provided with ample provisions and would monitor the corn fields until the rest of the community returned. Many Indigenous communities also made abundant use of signed languages, which allowed Deaf people to communicate with few barriers. Though disabled people might take on unique roles in Indigenous societies, systemic discrimination was uncommon.

That said, what we might now recognize as disability could sometimes be understood as an appropriate consequence for a transgression against the community or the natural order. An over-eager Umo^{n}ho^{n} hunter who rushed a buffalo herd, for example, was “crippled for life” when his horse fell on him, an incident “regarded as a supernatural punishment of his irreverent action in interrupting the prescribed order of procedure” (Fletcher & La Flesche, 1911, pp. 281–2). In other cases, bodily difference might be deemed the result of an encounter with spiritual power. Lavonna L. Lovern and Carol Locust (2013) write of an infant born with an “open spine” (p. 97). A healer explained that when the mother was pregnant, she must have sat beneath a tree whose trunk had been split open by lightning, but this spiritual disharmony could be rectified through ceremony. If there were a category we could call disability – difference, combined with stigma or the denial of full membership in the community – it had less to do with inherent judgements about a particular body or form of cognition and much more to do with the larger set of relations that surrounded the person and their harmony with the social and spiritual worlds.

European arrivals brought substantially different frameworks of disability, though these too varied across time, space, and cultural context. In Massachusetts in 1641, for example, the law assured that no one would be made to fight in wars or work in the public service if they were impeded “by want of yeares, greatnes of age, defect of minde, fayling of sences, or impotencie of Lymbes” (The Body of Liberties, 1641, s. 6; Nielsen, 2012, p. 21). Many more of this document’s clauses also addressed matters of perceived legal competence. For example, the law limited the right to make wills and testaments, or otherwise alienate property, to those “which are of the age of 21 yeares, and of right understanding and meamories” (s. 11; Carey, 2009, p. 38), while land and estate transactions involving “any woman that is married, any childe under age, Ideott, or distracted person” needed to be ratified by a General Court (s. 14; Nielsen, 2012, p. 21). Other colonies and, later, states enacted similar provisions that prevented such individuals from entering into contracts, marrying, serving on juries, or voting and also excused them from some forms of legal prosecution. These categories of social exclusion and protection had a fluidity that encompassed various permutations of sex, age, and cognitive and physical difference. Yet as Allison Carey (2009) points out, “[w]hile offering some degree of protection, the exclusion from rights simultaneously made individuals vulnerable to segregation, marginalization, and abuse” (p. 2).

Even before the United States was constituted as an independent nation, its civic leaders also sought to exclude those whom they perceived as likely to be dependent; this category was not self-evident and was often characterized by some combination of poverty and supposed infirmity. As early as 1701, for example, Massachusetts passed a statute to prevent “the poor, vicious and infirm” from arriving in the colony. The regulations required the master of each ship to post bonds for arriving passengers who were deemed “lame, impotent, or infirm persons, incapable of maintaining themselves,” with the guarantee that the town would not be charged with their support. If the captain would not or could not provide this, he would have to return the passenger to their port of embarkation (Baseler, 1998, p. 71; Nielsen, 2012, p. 27). For families already living within the colonies, however, infirmity was a common occurrence, given the likelihood of serious injury or illness over the course of one's life. Such infirmity, however, would not necessarily have translated into social ostracism; in many cases, families would retain strong bonds with disabled relatives. Notwithstanding some notable examples of exclusion, disabled people often remained emotionally and spiritually significant members of the community and might continue to take on some of the diverse types of labor required in a pre-industrial society (Nielsen, 2012).

There are, in fact, some well-documented historical examples of environments in which physical, sensory, or cognitive difference did not necessarily translate into any obvious exclusion or discrimination. On the isolated island of Martha's Vineyard, for example, a preponderance of Deaf residents – estimated at as many as 1 out of every 5 people in one neighborhood and perhaps 1 in 156 across the island as a whole in the nineteenth century – meant that many hearing people on the island learned sign language (Groce, 1985, p. 42). Deaf residents experienced life with few barriers to participation. They held political office, engaged in social activities, and otherwise existed seamlessly in Vineyard culture. This continued until the rise of residential schools for the Deaf and the island's growing integration with the mainland, which ruptured the society's enclave existence. In other cases, a supportive family and community ensured that a person with a disability was deeply integrated into local life. Penny Richards (2014), for example, examines the life of Thomas Cameron, a white man from a prosperous slave-holding family in nineteenth-century North Carolina. Planter society, writes Richards, "admired individual achievement and intelligence but also upheld such interpersonal, communal ideals as honor, duty, usefulness, and affection" (p. 38). Cameron, whom Richards understands as having a developmental disability, consequently experienced a high level of social connection, with networks of kinship, business, and religion that "generally served [him] well throughout his life" (p. 38).

In the absence of family or community integration and support, however, discrimination and ostracism were likely to occur, and they often fell along lines of preexisting social tension or prejudice. When Anne Hutchinson, for example, dissented from conventional theological beliefs in Puritan Massachusetts Bay Colony, her non-normative births were singled out for particular condemnation. They were evidence, in the Puritan mind, of God's punishment for her transgressions and evidence to the historian of the intersection between disability and Hutchinson's unsettling of the colony's religious, gender, and political norms and power structures (Nielsen, 2012). Similarly, people with illnesses or developmental disabilities who fell outside the provisions of family support and resources might find themselves confined to the hospital or almshouse, institutions that were increasingly present in the colonies in the eighteenth century. Life in these facilities was notoriously harsh, with bad food, corporal punishment, forced labor, and often torturous and confined conditions. There were important exceptions, however: Laurel Daen, for example, details a system of boarding sick and disabled "strangers" (people without settlement rights) in residents' homes in late eighteenth-century Massachusetts (2020). Disability remained a highly relational experience, defined less by the absolutes of one's body, mind, or senses than by one's connections, support, and belonging in a community.

Race and Slavery

Ideas about disability were also deeply interconnected with ideas about race. Stefanie Hunt-Kennedy (2020) notes the emergence of legal codes in seventeenth-century Virginia, as well as the Caribbean, that made freedom or slavery contingent on the mother's status; these descended, she argues, from beliefs about supposed African monstrosity and an obsession with maternal imagination and maternal inheritance. "The English notion that blackness was a heritable and racial form of monstrosity," she writes, "remained a feature of seventeenth-century English conceptualizations of Africans and their descendants, as a timely and advantageous justification for Africans' subjection in the transatlantic economy" (p. 16).

Such intersections between race and disability would continue to be used to justify American slavery in even more explicit terms through subsequent centuries. As Jenifer Barclay (2014) explains, "whiteness claimed whole, able bodies and rational, sound minds as its ontological terrain, the embodiment of not only 'normal' but also 'perfect.' In contrast, blackness represented various forms of defectiveness and abnormality – one might say *disability* – whether these characteristics were real or imagined, visible or invisible, physical or psychological" (27). Noted writers invoked disability as justification for the racist denial of rights and freedoms, often using ostensibly medical rationale. Slavery's defenders, for example, drew on assumptions that Black people were intellectually deficient and thus unable to participate as equal citizens in American society, enforcing a version of liberal citizenship that hastened to exclude people who did not fit the model of a white, supposedly self-governing, intellectually engaged, and landholding man. When the 1840 census appeared to show, inaccurately, a higher rate of mental illness and "idiocy" among Black people in free states, Secretary of State and former Vice President John C. Calhoun (1844/1859) concluded that "in all instances in which the States have changed the former relation between the two races, the condition of the African, instead of being improved, has become worse" (p. 337; see also Baynton, 2001, pp. 37–38). Physicians and intellectuals also undergirded their racist proclivities by appealing to Black pathology and disability. Perhaps most famously, the southern physician Samuel Cartwright (1851) described two major kinds of illness among enslaved people. "Drapetomania," a portmanteau of the Greek words for "a runaway slave" and "mad," was a "disease of the mind causing [the enslaved person] to abscond" and was ostensibly "well known to our planters and overseers" (p. 707). The cure was supposedly some balance of "humane" treatment, an insistence on the enslaved person's submission, and, if necessary, preventive whipping. Similarly, "Dysæsthesia Æthiopis" was Cartwright's invented medical condition for a kind of "rascality" or misbehavior supposedly common among free Black people and on "badly-governed plantations" (pp. 709–10; Baynton, 2001, p. 38). This might involve sleeping during the day; sabotaging tools, crops, and clothing; raising disturbances; and being seemingly insensible to pain when punished. Again, the solution included physical stimulation through hard work and whipping oil into the skin.

Such grotesque examples of invented medical diagnoses and violent “treatment” demonstrate how labels of pathology and disability, increasingly under the authority of the medical profession, operated as a way to exclude people from freedom and the rights of US citizenship. The proposed “cures” similarly tended to benefit those in power, whether those cures involved medical treatment, institutionalization, or, in the case of enslaved people, more forced labor. Moreover, by setting up a rough equivalency between Blackness, disability, and denial of rights, this discourse pushed some reformers to work within these same logics. Those advocating for abolition, for example, might highlight slavery’s tragically disabling effects or contend that Black people did in fact possess the necessary rational capacity and ability to assume the full rights of citizenship. Many anti-slavery reformers appealed to the sentimental image of the “crippled” bondsperson, reinforcing an idea of disability as a dehumanizing state, while abolitionist Frederick Douglass reportedly asserted at the Seneca Falls Convention that rights had their basis in the “capacity of individuals” (Stanton et al., 1881, vol. 1, p. 87; Nielsen, 2012, p. 52; Baynton, 2001, p. 44). The goals of freedom and citizenship, whether for enslaved people or women, were all too often still expressed in ableist terms. Disabled Black people might even be pressed to make their careers as performers by playing to the persistent tropes of racism and ableism. Under the management of a white man, the Black child performer Oscar Moore, known publicly as “Blind Oscar Moore,” toured the United States in the late 1880s and 1890s. Moore would answer obscure trivia questions from memory, demonstrating what white audiences would have understood as an uncanny combination of Blackness, juvenile age, disability, and intelligence (Owens, 2020).

In practice, many enslaved people bore the results of physically disabling injuries and mistreatment, as well as the intergenerational consequences of trauma, malnutrition, and forced labor. Broken bones, missing fingers, scars, blindness, pellagra, tuberculosis, reproductive difficulties, and other ailments were the result of cruelty and poor living conditions, while enslaved people might also be deliberately mutilated as punishment or to prevent repeated attempts to run away. Disability affected the “soundness” and thus the value of enslaved people, which slaveholders and traders determined through a calculus of assessments about fertility, behavior, and age, as well as other physical, mental, or sensory qualities. There is also evidence that in at least some cases, enslaved people would try to use disability as a tool of agency in the marketplace or to negotiate the terms of their enslavement to the extent that they could. Moreover, though disabled enslaved people might receive some treatment from white doctors, many also had their own methods of care, such as herbal or spiritual remedies, claiming community and self-determination, however constrained, in the midst of oppression (Boster, 2013).

Slaveholders were legally required in most cases to provide basic subsistence for aged or disabled bondspeople, and in an effort to prevent pauperism, laws banning the manumission of disabled slaves were widespread. Many disabled enslaved people continued to fill roles on the plantation until they died, whether caring for children, working as watchmen, or doing manual labor. Yet it is also clear that slaveholders sometimes sought to rid themselves of the responsibility of caring for people who could not labor to their expectations. Some might reduce or even withhold disabled enslaved people's rations, clothing, and shelter, leaving their fellow bondspeople to care for them, for example. There is also evidence of owners selling or hiring out aged or disabled bondspeople for medical research (Boster, 2013). Disability might be understood as a matter of differences of body, mind, or senses, but it also shaped and was shaped by other categories of power, privilege, and citizenship. Its meanings could shift in different contexts, with dramatic consequences for individuals' lives.

Industrial Society and Medical Authority

Profound changes in social and economic life in the nineteenth century further crystallized the exclusion of many disabled people from the American body politic. Sarah Rose, in fact, has argued that "disability" emerged as a newly coherent category as a result of the transition to industrial capitalism. Mechanized work called for "intact, interchangeable bodies" (Rose, 2017, p. 2), and wage laborers in urban settings were less able to support relatives who did not readily conform to the demands imposed by this new form of economic and social organization. Massive growth in the field of prostheses after the Civil War and World War I also shows a concomitant reliance on technology to return disabled soldiers, as well as injured workers, to productive paid labor, the new arena for the adjudication of citizenship in American life.

These processes, too, were shaped by ideas about race. Ellen Samuels, for example, argues that unsettling changes in social and economic life in the nineteenth century led to the emergence of "fantasies of identification," as Americans sought to "definitively identify bodies, [and] to place them in categories delineated by race, gender, or ability status." These categories, which often overlapped with and defined one another, were ostensibly based in verifiable biological fact, but in reality they rested on shifting, and scientifically specious grounds (2014, p. 2). Similar trends continued in the twentieth century. For instance, the Federal Board of Vocational Education (FBVE), established in 1917 and responsible for rehabilitating soldiers into workers, routinely "conflat[ed] disability with blackness," seeing disabled Black soldiers as "defective by definition" (Lawrie, 2016, p. 10). Training programs focused largely on agricultural and industrial education, and physicians would attribute many veterans' disabilities to venereal disease or tuberculosis rather than wartime service. These men might thereby be disqualified from full access to programs and compensation that could have otherwise upset racial hierarchies and undermined the property and literacy requirements that barred many Black people from voting in the Jim Crow South. Paul Lawrie (2016) concludes that "[t]he FBVE's characterizations of blacks as congenital racial cripples rationalized the economic and social self-interest of southern and national white supremacy" (p. 121). Hospitals, moreover, looked for evidence of African American degeneracy and deviance in former soldiers; many of these men were denied anything but palliative care, and in some cases, people with mental and physical disabilities were confined in carceral institutions. Lawrie cites a case in which the Red Cross and Veterans Bureau sent 30 African American veterans with tuberculosis to the Central State Hospital for the Criminal Insane in Nashville, with the justification that "their condition could be attributed to a uniquely racial mental affliction" (qtd. in p. 131).

In the process of America's westward expansion, categories of disability also justified exclusion or violent cure for Indigenous people, who were often cast as disabled in some way. Indigenous people might be incarcerated in the Canton Asylum for Insane Indians, for example, which operated from late 1902 to 1934 in South Dakota. The processes of diagnosis were deeply dubious: they often transmuted resistance, struggle, and dislocation, as well as authorities' stereotypes, prejudices, and exploitations, into categories of disability and thus disenfranchisement (Burch, 2014). In the first decades of the twentieth century, moreover, competency commissions evaluated Indigenous people's capacity to hold the patents for their own land. These commissions assessed people on their physical and mental ability, education, language skills, financial history, and blood quantum, among other categories. The criteria and calculus for "competency" were often improvisational and opportunistic, used to satisfy Americans' desires for land or control or their sense of self-righteous humanitarianism. Disability could be weaponized as tool of exclusion and dispossession in America's westward settlement.

As the United States expanded – both geographically and in terms of the reach of government power – states and the federal government alike became more explicit in their deployment of medical and eugenic authority. Rather than simply excluded from the rights of liberal citizenship, disabled people would be eliminated from American society altogether. Immigration legislation, for one, cast an increasingly wide net of discrimination (Baynton, 2001). The 1891 Immigration Act barred "[a]ll idiots, insane persons, paupers or persons likely to become a public charge, [and] persons suffering from a loathsome or a dangerous contagious disease," as well as criminals and polygamists (s. 1). The 1907 legislation went further, listing "[a]ll idiots, imbeciles, feeble-minded persons, epileptics, insane persons, and persons who have been insane within five years previous," as well as people with two or more previous attacks of insanity, people with tuberculosis or any other "loathsome or dangerous contagious disease," and people deemed "mentally or physically defective" in a way that "may affect the ability of such alien to earn a living." "[P]aupers" and "persons likely to become a public charge" were similarly excluded (s. 2). Flexible interpretation allowed these labels to be applied unevenly, facilitating and compounding discrimination along other axes, including sexuality, gender, and class, as well as race and ethnicity (Baynton, 2001; Dolmage, 2018). As Jay Dolmage (2018) explains, "[i]n the heterotopia of deviation created at Ellis Island, undesirable bodies were shaded with attributions of disability; and disabled bodies were 'raced' as nonwhite, or as disqualified whites" (p. 17).

Eugenic sterilization programs also arose in the opening decades of the twentieth century, as concerns about white racial degeneracy and amelioration evolved into a broader set of associations between heredity, disability, and supposed criminality, social deviance, and dependency. The control of reproduction was ostensibly a way to contain and ultimately eliminate these perceived social ills. While the first eugenic sterilization law was passed in Indiana in 1907, such programs multiplied in subsequent decades, particularly as psychologists such as Henry H. Goddard, Director of Research at New Jersey's Vineland Training School for Feeble-Minded Girls and Boys, promoted new ideas about the hereditary nature of feeble-mindedness. Standardized intelligence tests offered a new diagnostic tool, and Goddard famously coined the term "moron" to refer to a "high-grade feeble-minded person" (Goddard, 1912, p. 11). Estimates of the rate of feeble-mindedness varied, as did the exact parameters of various proposed diagnostic sub-categories, but the label was increasingly associated with susceptibility to criminality, antisocial behavior, and sexual depravity. Most troublingly for reformers, some "feeble-minded" people might be indistinguishable from "normal" members of American society, posing an invisible menace. Compulsory sterilization laws received their greatest boost, however, with the Supreme Court case Buck v. Bell, in 1927. Carrie Buck, a young resident of the Virginia State Colony for Epileptics and Feebleminded, was targeted for compulsory sterilization on the basis of feeble-mindedness, a diagnosis whose danger to society was seemingly confirmed by Buck's already having given birth to a daughter, Vivian, out of wedlock. The state of Virginia selected Buck's case as a testing ground for the legality of their sterilization law, and it was confirmed by an 8–1 majority decision. By the 1930s, more than 30 states had sterilization laws on the books. California alone was responsible for approximately 20,000 out of the 60,000 sterilizations that are known to have occurred across the United States in the twentieth century (Stern, 2016, p. 115).

Sterilization, perhaps unsurprisingly, targeted people who were already socially vulnerable. Women made up approximately 61% of sterilizations by the early 1960s (Carey, 1998, p. 84), and studies of California's sterilization archive have demonstrated that people of Mexican origin were sterilized in disproportionate numbers (Lira & Stern, 2014). Though many compulsory sterilization programs faded after World War II, they did not disappear entirely. Between 2006 and 2010, for example, at least 148 women in California prisons, the majority of whom were Black and/or Latina, were sterilized without appropriate consent (Jindia, 2020), and activists and advocates around the country continue to seek reparations for decades of forced sterilization. Fears about uncontrolled sexuality, racialized reproduction, and social deviance shaped and continue to shape experiences and understandings of disability.

Reclaiming Rights, Resisting Ableism

In the twentieth century, many disabled people have increasingly embraced not only shared identities but also shared political power, seeking liberation from the discrimination and disenfranchisement that have historically characterized so many experiences of disability. Yet this work has happened in sometimes fragmented ways. As activist Paul Longmore explained in an oral history, "there is no single homogeneous disability rights movement. There really are at least a half dozen movements about disability rights and each one reflects the interests and issues and concerns and needs of a particular disability constituency" (2006, pp. 161–2; Pelka, 2012, pp. ix–x).

Though some clubs and publications for disabled and Deaf communities existed in the nineteenth and early twentieth centuries, one of the first major activist organizations for disabled people was the New York-based League of the Physically Handicapped, which operated between 1935 and 1938 and opposed disability discrimination in the Great Depression's job relief programs. Through protest and political meetings, they were able to win some inclusion for disabled people in New York City's Works Progress Administration jobs, for example, but they had more difficulty securing victories at the federal level. Using slogans like "We Don't Want Tin Cups. We Want Jobs," the League's members pushed back against the stigma, assumptions of non-productivity, and social ostracism that had long been associated with disability in industrial America (Longmore & Goldberger, 2000, p. 904).

Other organizations, such as the National Federation of the Blind and the American Federation of the Physically Handicapped, founded in the 1940s, also focused on disabled people's exclusion from the workforce. The latter organization was successful in pushing for the 1945 declaration of "National Employ the Physically Handicapped Week," as well as the establishment of an attendant committee, later known as the President's Committee on Employment of People with Disabilities; the Office of Disability Employment Policy assumed its responsibilities starting in 2001 (Jennings, 2009). This activism explicitly worked within frameworks of liberal American society that privileged work as a pathway to citizenship and sought to challenge the prejudices that excluded disabled people from the workforce.

Some disabled people and communities also created material worlds that resisted ableism and the limitations of the mainstream built environment. Established in 1958 out of the community of the Toomey Pavilion rehabilitation center in Cleveland, the *Toomey J Gazette* shared tips for fashioning do-it-yourself adaptive technologies. It was headed by a team of volunteer women, three of whom were disabled polio survivors (Williamson, 2019). Starting in the 1960s, many disabled Americans also began to present a united force against systems of oppression that excluded them not only from the labor market but also from education, public spaces, and civic life more generally. Activist Ed Roberts famously registered in classes at the University of California, Berkeley, in 1962, and his leadership attracted other disabled students. Ten years later, these young activists would be some of the core founders of the Center for Independent Living, a model of self-directed, community-based living for disabled people (Pelka, 2012). Other disability groups, including associations of psychiatric survivors, also emerged in this era: the Insane Liberation Front was founded in Portland, Oregon, in 1970, while similar organizations emerged in Boston and New York in 1971 and San Francisco in 1972 (Chamberlin, 1990). These activist organizations spoke out most ardently against harsh treatments like forced drugging and involuntary confinement. Disabled people labelled the authorities and institutions that traditionally claimed responsibility for them as oppressive and even violent and rejected limitations on their rights and freedoms.

Protest also became an increasingly important tool for the Disability Rights Movement during the 1970s and 1980s; these activists were inspired, at least to some extent, by the Civil Rights Movement. When the Rehabilitation Act of 1973 was passed, for example, it included Section 504, which prohibited discrimination on the basis of disability by any public or private entity receiving federal funds. Without regulations to guide its implementation, however, the law would offer little legal leverage for disabled people. In 1977, a coordinated, cross-country effort by activist groups resulted in protests at US Department of Health, Education, and Welfare buildings across the country, with the goal of accelerating the regulations' publication. The largest protest was in San Francisco, where activists occupied a floor of the building for nearly 4 weeks. Recognizing a shared struggle against oppressive structures of power, the Black Panther Party – two members of which participated in the sit-in – offered its support (OToole, 2015). In a similar vein of protest, in March of 1988, students at Gallaudet University in Washington DC barricaded the campus, frustrated by the appointment of a hearing university president and a long history of hearing leadership and administration. They called for the appointment of a Deaf president, as well as the reconstitution of the Board of Trustees to ensure a Deaf majority of members. The protest was successful, and I. King Jordan became the university's first Deaf president (Christiansen & Barnartt, 1995).

While numerous local and federal laws addressed disability rights through the 1980s, the best-known legislative achievement of the Disability Rights Movement in the United States is the Americans with Disabilities Act (ADA), passed in 1990. The ADA, a comprehensive work of civil rights legislation, lays out specific requirements for non-discrimination in employment, as well as the accessibility of public services, transportation, built environments, and telecommunications, for example. While many celebrated its scope, as well as its requirements for personalized, reasonable accommodation, the ADA has not been without its critics. Some observers have questioned the ADA's neoliberal orientation. Its provisions against employment discrimination, for example, do little to address low wages and job instability for many disabled workers, and disability benefits remain insufficient (Russell, 2003). Pursuing legal recourse for ADA violations remains onerous. Moreover, in practice, the courts have narrowed the definition of disability, limiting the ADA's applicability, and the media has also often been unsympathetic to disabled plaintiffs, suggesting that the fundamental structures that privilege conformist labor, wealth, and the powerful remain undisturbed (Schriner & Scotch, 2003). Experiences of disability, and even who counts as disabled, continue to be defined and shaped by social and political norms and forces, and many disabled people pair their efforts toward civil rights and inclusion with efforts to build their own communities and alternative social structures.

Conclusion

Disabled Americans continue to advocate for fair treatment and full social inclusion and access while also embracing, in many cases, unique disability identities and communities. The history of disability in the United States demonstrates the category's breadth, malleability, and intersection with other structures of power, prejudice, and discrimination, but disability has also proved a powerful rallying point for individuals to assert belonging and rights and work to end ableism in American life. The field of disability history continues to expand, with a growing presence in classrooms, museums, websites and documentaries, conferences, and scholarly publications. Future work will continue to explore the rich histories of disabled people's lived experiences, especially across other, intersecting categories of identity, as well as disability's political and discursive significance in American history more broadly.

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Disability History of Modern East Asia: An Overview

10

Wei Yu Wayne Tan

Contents

Abstract

A disability-based approach to history (disability history) gives us perspectives on historical ideas of disability in modern East Asian societies. This chapter will emphasize three main areas: (1) disability, science, and medicine; (2) disability, law, and activism; and (3) disability and popular culture. In this chapter, the modern period is taken to mean the nineteenth century and thereafter, and the focus will be on China, Japan, and South Korea.

Keywords

Disability · Disability history · Disability studies · China · Japan · South Korea · Modern East Asia · Modern history · Modern societies

Introduction

A disability-based approach to history (disability history) gives us perspectives on historical ideas of disability in modern East Asian societies. This chapter will emphasize three main areas: (1) disability, science, and medicine; (2) disability, law, and activism; and (3) disability and popular culture. In this chapter, the modern

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period is taken to mean the nineteenth century and thereafter, and the focus will be on China, Japan, and South Korea (where “Korea” instead of “South Korea” is mentioned, it refers to the Korean peninsula and its inhabitants).

The social model in disability studies informs the general understanding of disability in this chapter. This model recognizes that society creates disability, and that disability is inseparable from the environment or system in which it is created (Adams et al., 2015). This idea about the social and political construction of disability can also be incorporated into the broad understanding that a society and its culture sustain disability (Waldschmidt, 2018).

This chapter’s historical approach validates the relationship between disability and society and between disability and culture. It will become clear that in each modern East Asian society, like in other modern societies around the world, the social, political, ideological, and medical realms of culture have defined disability as a concept and as an experience.

Disability and Its Contexts

1. Disability, Science, and Medicine

The classification of disability in East Asia today generally recognizes the categories of physical, mental, and intellectual disabilities. However, in the premodern (pre-nineteenth century) eras, there was no standard idea of what made up disability nor a designated category of disability in the scientific or medical vocabulary. What we think of as disability today has to be reinterpreted through the lens of the history of medicine of those eras, because disability was regarded as disease and illness. This section surveys the relationship between disability and medicine in premodern East Asia and the relationship between disability and science and medicine in modern East Asia from the nineteenth century through the early twentieth century.

China was the main source of medical thought and practices in premodern East Asia. Through long periods of intercultural exchange, Japan and Korea developed their own styles of medicine based on Chinese sources. *The Yellow Emperor’s Inner Classic*, which dates from the first century BCE or so, was one of the earliest known medical texts in China (Scheid, 2015). That text had tremendous influence on medical thought not only in China but also in Japan and Korea over many centuries. We should note that varieties of Chinese medicine developed within the respective traditions of China, Japan, and Korea (Cook, 2020; Suh, 2017; Trambaiolo, 2013).

The Yellow Emperor’s Inner Classic represents the traditional model of Chinese medical thought. The human body was described as a system of “organs” and “viscera” (we would recognize some of them as organs in modern human anatomy) linked through networks of conduits. Blood and *qi* (breath) flowed along these conduits, and health depended on their flow (Scheid, 2015). Illness could arise, for example, when there was “fullness” or “emptiness” (overabundance or deficit) of *qi* in the organs and viscera or when “winds” that caused disease invaded the body (Kuriyama, 2006). The human body was also understood to be more than a closed, corporeal body in many ways, because it embodied elements of the cosmos and functioned in synchronization with seasons and cycles of change (Kuriyama, 2006; Scheid, 2015). Even today, these interrelated concepts of health and illness continue to be important characteristics of traditional medical thought in East Asia.

The understanding of mental disability, among other disabilities, is one important example that shows how the frameworks of understanding disability changed as East Asian societies evolved. Although current studies of disability urge us to delink disability from medical perspectives, studying mental disability in earlier time periods, in fact, must involve studying the language used in medical sources from those times. In premodern China, medical theories outlined various causes of mental illness. Before the eleventh century, for example, mental illness was thought to be caused by "winds" that harmed the body (Baum, 2018). This is clear evidence of the influence of medical sources such as *The Yellow Emperor's Inner Classic*. Later medical theories, such as those of the Qing period (1644–1911), emphasized the role of mucus and fire in the chest in causing disorders that could affect the heart, which was the site of the body's "mind" (Baum, 2018). Because the "mind" was believed to be inseparable from the physical body, and from the vital flow of blood and *qi* around the body, treatments of mental illness not only aimed to break down mucus but also to restore the balance and flow of life's essence in the body's system.

Medical scholars of premodern Japan and Korea also employed the medical vocabulary of Chinese medical scholars in their approaches to mental illness. In Japan, during the Tokugawa period (1600–1868), some medical scholars linked the stagnation of *ki* (the Japanese reading of *qi*) in the body to emotional and mood changes and to irregular and even immoral behaviors (Kitanaka, 2010). This manifestation of psychological, behavioral patterns hints at clinical symptoms of what could have been mental depression. There were scholars at that time who argued that stagnated *ki* led to the dysfunction of the liver, the organ that was understood to control emotions: when stagnation set in, it could fuel "fire" in the liver and destabilize a person's emotions (Daidoji, 2013). In Korea, during the Chosŏn period (1392–1910), there were also scholars who theorized mental illness as illness caused by "fire," and the general population knew mental illness as "fire illness" caused by unrestrained emotions (Yoo, 2016). It is common to find in popular religions across premodern East Asia the association of mental illness with spirit possession, and popular cures for mental illness included religious exorcism through shamanistic rituals (Kang, 2006; Yoo, 2016).

Psychiatry was introduced from Europe and North America (global, cultural regions commonly referred to in the scholarship as the "West") to East Asia in the late nineteenth century, and its introduction is often seen as a turning point in the history of mental disability. Psychiatry was one of the representative branches of the new, Western medicine that catalyzed the acceptance of medicine based on modern human anatomy. While this may mean to some people that mental disability was "discovered" in the modern era of Western medicine, we may also argue that mental disability had existed for a long time but emerged as a new disability when the medical vocabulary and references changed.

In China, during the Republican period (1912–1949), psychiatry transformed the ways mental illness was treated. Psychiatry reoriented medical thought by emphasizing the brain, not the heart, as the organ of cognition, and clinical therapies were developed around this new psychiatric model (Baum, 2018). At the same time, traditional medical beliefs were not completely effaced by Western medicine, as many people found ways to appropriate familiar, historical practices. One notable social feature of that period was the founding of public mental institutions ("asylums"), such as the Beijing Municipal Asylum (Baum, 2018). As Baum (2018) points out, the early Republican Chinese penal code of 1912 was intended to delineate the place of criminals with mental illnesses in the nation's legal system. Public mental institutions offered a solution to shelter and confine them, and because those institutions were often poorly staffed and underfunded, the level of care was generally poor. Through social and legal measures to contain mental illness, government officials became more involved than before in the surveillance of deviant behaviors (Baum, 2018). Even so, the family remained the core unit of caretaking. This situation was quite similar in Japan as well.

Japan in the early Meiji period (1868–1912) took the lead in East Asia in adopting psychiatry. This was because Japan started to modernize its industries according to Western standards before the rest of East Asia could. The Japanese government studied the German model of medical education and spearheaded the reinvention of medicine in Japan (Kim 2014). Like in China, psychiatry in Japan overturned the traditional understanding of human anatomy and privileged new methods of investigating mental illness as psychological, cognitive disorder. Japanese students traveled abroad to Germany and Austria to study psychiatry and returned to Japan to take up the reins of teaching psychiatry (Kim 2018). Hospitals were new institutions of the Meiji period (Burns, 1997), as were mental institutions (Kim 2018). In the early twentieth century, psychiatry had become part of mainstream medicine, and at hospitals, experimental treatments of mental illness, such as shock therapies, were tested on patients (Suzuki, 2010).

Japan used laws to organize the national and local approaches to mental illness. The Custody Law Regarding People with Mental Illness of 1900 outlined the family's obligation to protect family members with mental illness. However, the outcome was often deplorable because, as a standard practice, many families inhumanely confined those family members in cages at home (Nakamura, 2013). Later, in 1919, the Mental Hospitals Act aimed to offer public support for people with mental illness through hospitals (Kim 2018). The Japanese government also tried to reform the medical system in Korea, after Japan's annexation of Korea in 1910 (Japan's colonial rule of Korea ended in 1945 after World War II). One of the Japanese government's tasks was to oversee the psychiatric care of people with mental illness through the Government-General Hospital (Yoo, 2016). However, due to limited resources, most people with mental illness in Korea, and in Japan, had to be cared for through their own means at home, and treatments at mental institutions did not replace home-based care.

From the late nineteenth century, ideology in East Asia also played a major role in influencing ideas about able-bodiedness and hence ideas about who was able-bodied. In this regard, the ideology was often flawed and prejudiced, because it claimed to use science to prove why some categories of people were more able than others. The rhetoric about race, society, and culture pursued certain reasoning to achieve social and political goals. Hence, as we survey disability history, we have to understand that a society's ideological purpose informs notions of disability.

Darwinism (Darwinist thought) was introduced to East Asia in the early 1870s. Like their European and North American contemporaries, intellectuals in East Asia became interested in exploring the social dimensions of Darwinism – that is, they became interested in how evolution could explain social change and provide a blueprint for society to advance itself (Chung, 2014; Cross, 1996). Social Darwinism, this new area of thought, generated vigorous debates in the intellectual and political arenas. The political environment of East Asia in the late nineteenth century was ripe for Social Darwinism to feed imaginations of national (and nationalistic) agendas. Japan saw the depredations by foreign powers that had befallen the Qing dynasty as a cautionary tale of what could happen to a society that could not defend itself against global threats. Japanese intellectuals aimed to turn Japan into a "strong state" in "the survival of the fittest" (Godart, 2017) and explicitly invoked "race" as an axis to organize the rhetoric of Japan's "racial" superiority (Chung, 2014). At the same time, intellectuals in China and Korea wanted to translate the ideological potential of Social Darwinism into action, to mobilize their respective nations' populations and overcome their "weak" national statuses (Chung, 2014; Tikhonov, 2016).

From the start, eugenic thought (ideas about heredity, birth, and genes) in East Asia was central to discussions of Social Darwinism. Eugenicists argued that those members of society deemed to be the most "useful" (often measured in economic and military terms) had to fulfill society's mission to thrive. Those intellectuals aimed at projecting a masculine image of strength, vitality, and courage of their nations and recognized that women played a necessary role because of their potential to bear "healthy" children and nurture them. Gender was a category that was regulated because of its social and political significance. In Japan, laws from the 1870s through the early twentieth century were revised to define abortion as a crime (Burns, 2013). From the 1920s, when eugenics gained pace, tensions developed between advocates of population control, who supported measures such as birth control, and their opponents (Kim 2008). Advocates of women's issues, including some women, even challenged the patriarchal framing of gender (Otsubo, 2005). In Korea's colonial period, and similarly in those years in China, birth control was debated, because although it was viewed as a means to propagate and enhance "good" racial traits, it could cause low population growth and be detrimental to a nation's strength (David, 2018; Kim 2008).

Clearly, in these East Asian contexts of Social Darwinism and eugenics, disability was interpreted to be undesirable. Associated with "weakness," disability was strongly discriminated against as a negative factor in a nation's plan to cultivate an "able-bodied" population. While societies have a duty to protect their populations, including people with disabilities, the reality is that across East Asia, there was little commitment of resources to ameliorate the well-being of people with disabilities in the period leading up to World War II.

2. Disability, Law, and Activism

World War II had a devastating toll in East Asia in terms of the scale of destruction it caused. The war also permanently rearranged power dynamics in that region. This section looks at disability in East Asia in the post-World War II period and discusses examples of the intersection of law and activism in disability history.

The immediate postwar decades (1940s–1970s) were significant in Japan's disability history. After Japan's surrender to the United States, the Supreme Commander of the Allied Powers (SCAP) oversaw the administration of Japan. During the occupation, the SCAP regarded Japan's demilitarization, democratization, and economic reconstruction as priorities. As a result of the war, there were significant numbers of disabled war veterans, and poverty was a pressing social problem. New laws had to be legislated and implemented to raise the standard of living. The SCAP, in conjunction with the Japanese national government, used legislation to help people regain their livelihoods (Pennington, 2015). As Lee Pennington (2015) points out, the Livelihood Protection Law of 1946 did not create privileges for disabled war veterans. This was a political choice. The SCAP was clear about not rewarding wartime service, particularly because Japan had to be held accountable for its role in World War II.

In 1949, Japan passed the National Welfare Law for People with Physical Disabilities, the first law in Japan that was centered on disability and welfare (Pennington, 2015). Under that law, civilians with physical disabilities and disabled war veterans were regarded equally, and the main goal was to help people with physical disabilities gain access to rehabilitation and other social services (Yamada, 2013). After the occupation, as disability became a mainstream category in welfare, people with other disabilities were legally recognized. The National Law for the Welfare of People with Intellectual Disabilities of 1960 and the Basic Act for People with (Physical) Disabilities of 1970 provided the framework for legal approaches to disability (Stevens, 2013). Later, in 1993, the original Basic Act for People with (Physical) Disabilities was updated to include mental and intellectual disabilities under the same label of disability.

South Korea's postwar disability history, like Japan's, was influenced by democratization and disability rights activism. The Korean peninsula was divided by the USSR and US into North and South Korea at the end of World War II in 1945; the Korean War (1950–53) deepened the conflict between the two Koreas. After the Korean War, South Korea was ruled by military dictatorships until the 1980s when it started to transition to democratic rule. South Korea's democratization, though delayed compared with Japan's postwar transition, proceeded apace. As that happened, there were growing demands by activists for the expansion of disability welfare and laws. Activists used the 1988 Paralympics hosted by South Korea as a context to draw attention to the existing social challenges for people with disabilities (Kim 2017), and by the 1990s, their activism had led to changes in the Disability

Welfare Law, the enactment of the Law to Promote Employment Among People with Disabilities, and the increased representation of people with disabilities through the Korea Federation of Organizations of People with Disabilities (Arlington, 2020). In Japan, the Green Grass Association, an activist group representing people with cerebral palsy, led disability rights movements and was joined by other groups, such as those advocating independent living for people with disabilities and those supporting deaf culture (Nakamura, 2006; Stevens, 2013). As activism gathered momentum in Japan and South Korea, activists achieved some success in lobbying their governments for antidiscrimination legislation to protect the rights of people with disabilities and facilitate their participation in society (Arlington, 2020; Heyer, 2015; Stevens, 2013).

China's postwar experiences, like South Korea's, were tumultuous right after World War II because of postwar conflicts. China was plunged into civil war, and in 1949, the Chinese Communists emerged victorious over their Nationalist rivals. After the civil war, the Chinese Communist Party's (CCP) Chairman Mao Zedong was instrumental as the leader who set China on a new path to accelerate economic and industrial growth. Government campaigns such as the Great Leap Forward of the late 1950s (which was part of the series of Five-Year Plans) were intended to rebuild China's foundations and, also, reorganize Chinese society around a collective sense of nationhood – a nationhood that brought together individuals under a sovereign, national will. Amid the developments that unfolded was the collectivization of Chinese society through units called collective brigades. This collective social arrangement fostered new bonds of belonging among the Chinese population and seems to have supported people with disabilities (Fjeld & Sagli, 2011).

A new phase of disability history in China began in the 1980s. Deng Xiaoping, the leader of the CCP who succeeded Mao, recalibrated Mao's policies to pursue state-controlled liberalization of Chinese society, particularly China's economy, and that included "re-opening" China to the world. Disability in China drew more public attention, generally because of greater awareness of disability following the United Nations' Year of People with Disabilities in 1981 (Kohrman, 2005). In both South Korea and Japan, the United Nations' recognition of disability also raised awareness of disability, and the increased awareness informed the legislative context of disability (Arlington, 2020; Heyer, 2015). In 1982, advocates in China formed the Club for Youths with Disabilities (Disabled Youth Club), one of the earliest activist groups whose work cut across categories of disability (Kohrman, 2005). The China (Chinese) Federation of People with Disabilities was founded in 1988. Deng Pufang was a founding member, and his status as Deng Xiaoping's son was very likely a reason why the federation had support from within the Chinese government (Kohrman, 2005). This disability federation is an example of the system that Matthew Kohrman calls modern Chinese "biobureaucracy," government and non-government institutions that share bio-medical ideals of rehabilitating people with disabilities, whom they regard as people with "damaged," "sickly" bodies (Kohrman, 2005). Using his influential status, and building on the success of the disability federation, Deng Pufang, along with others close to him, played a critical role in cementing the Law on the Protection of People with Disabilities in 1990. In recent years, China has been working toward reforming its disability welfare system so as to more equitably distribute resources across rural places, which tend to have less resources than urban areas to cope with disability, poverty, lack of healthcare, and rising insurance costs (Fjeld & Sagli, 2011).

While many of the laws in postwar East Asia in their respective ways appear to have helped to make disability acceptable, there is a long history of negative attitudes toward disability. In fact, some laws even deprived people with disabilities of their rights. One of Japan's most restrictive laws was the National Eugenics Law of 1940. The 1940 law, which was heavily influenced by eugenic thought and laws of Nazi Germany, legalized the sterilization of people who had hereditary medical and social conditions. For example, Japanese eugenicists regarded alcoholism as a social condition with hereditary causes, and people with mental and intellectual disabilities were among those identified by the 1940 law for forced sterilization (Kato, 2009; Robertson, 2002). It is said that during the wartime period in Japan, just over 530 people with disabilities were forcibly sterilized, and until more information emerges, this figure may suggest that the scale of forced sterilization was limited because of other wartime priorities (Kawashima, 2013).

Even in the postwar period in Japan, eugenics dominated the mindsets of scientific, medical, and government officials and had a devastating impact on the social and medical treatments of disability. Japan's Eugenics Protection Law of 1948 validated eugenic reasoning in legalizing abortion, though it cited maternal health as a reason for abortion (Kato, 2009). That 1948 law, an extension of the 1940 law, also expanded the scope of sterilization to make it legal to perform sterilization even on people who did not have hereditary conditions. For one, what was hereditary was not always scientifically proven or justified, because prenatal testing technology was limited (Kato, 2009). Both the 1940 and 1948 laws, from today's perspective, can be seen as being harshly punitive against people with disabilities – stigmatizing disability as medical abnormality, perpetuating social misconceptions of disability, limiting the reproductive rights of people with disabilities, and reducing a woman's role to that of giving birth to "healthy" babies. In 1952, the 1948 law was revised to make it legal for a woman to cite financial difficulty as a reason to have an abortion, making abortion also an economic choice (Kato, 2009). The law was finally abolished in 1996.

South Korea's postwar eugenic policies have a history that can be traced back to the Korean colonial period. Eugenic thought was introduced to Korea through Japan. While Korea did not have a eugenics law in that period that paralleled the 1940 law of Japan, the Public Health Office, a branch of the colonial government, oversaw efforts to create "strong," "fit" Koreans and even approved of sterilizing "unfit" Koreans (Kim 2017). Though Japan's official policy was to integrate Koreans into the Japanese population, hardline Japanese factions rejected the argument that Koreans were equals (Caprio, 2009). Korean eugenicists occupied a difficult intellectual position, because they could not read against the grain to openly espouse "superior" innate qualities of the Korean ethnicity. Yet they perhaps knew that although eugenic thought was discriminatory, it was still a useful ideological, rhetorical tool to explain how Koreans could become "more progressive" as a society. After World War II, the military government of South Korea revived eugenics in discussing ways to envision the physical, economic health of the Korean nation (Kim 2017). This was one motivation for introducing the Mother and Child Health Act of 1973. Abortion was already a crime from 1953, but the law of 1973 made abortion legal in certain cases, for example, when there was reason to suspect that an unborn child's parent had a hereditary disease – in this context, disability was the same as disease (Kim 2017). The law granted a physician the authority to recommend a patient's sterilization to health authorities should a hereditary disability be discovered or diagnosed. There was little recourse for a patient in such a situation. In 2019, the Constitutional Court of South Korea reversed the ban on abortion and ordered that the law be revised by 2020 (Choe, 2019).

China's history of postwar eugenic policies is part of the nation's history of population growth control and economic planning. During World War II, as living conditions were poor and the war against Japan was claiming the lives of many Chinese, the Chinese Communists saw high birth rate as necessary to compensate for population loss (White, 2006). After World War II, the CCP's drive to regenerate China's population strength influenced the nation-building process in the years between 1949 and 1952. However, as the CCP was planning the first Five-Year Plan (1953–1957), it had to rethink its approach to population growth. There were real concerns that uncontrolled, rapid population growth in the nascent nation could compound the problem of scarce economic resources (White, 2006). The CCP adopted a model of "birth planning," which was conceived as a practical plan to address birth control and as a response to reconcile competing demands for population growth and economic growth (White, 2006). Hence, "birth planning" was integral to China's postwar vision of industrialization that could be sustained by, and not undermined by, population growth.

From 1979, the one-child policy – the government policy of having one child per family – became a necessity and a reality in China. To enforce the policy, the CCP delegated government officials to keep track of birth rates and to order sterilizations to be carried out when necessary (White, 2006). Campaigns to sterilize the population spread across the nation, especially in rural places where a large proportion of the population lived. The policy had exceptions, and what was acceptable depended on how the provincial and local governments of areas where people lived responded to the policy. Between 1983 and 1989, as agricultural reforms were changing the ownership of lands and the organization of labor among the nation's peasantry, some places gave permission to families to have two children (White, 2006). The policy was also adjusted to apply to cases in which a family whose first child was a daughter could try to have a second child – this was a reflection of Chinese society's gender bias for sons. Disability was a significant factor in the interpretation of the policy. A family with a child with disability (or disabilities) could be allowed to have a second child, and this discrimination against disability was reflected again in the Law on Population and Birth Planning of 2001 (Fjeld & Sagli, 2011). Most recently, China has revised its policy, encouraging families to have up to three children to reverse the projected decline as a result of the one-child policy (Wee, 2021). It remains to be seen how disability will impact the future of this new policy.

The history of Hansen's disease (known in the earlier medical and historical literature as leprosy) can be examined in the modern context of eugenics laws in East Asia. Like mental illness, Hansen's disease is a medical condition that has received much attention, because of a history of controversial, discriminatory treatment – a history that can be traced to premodern sources. Though Hansen's disease is often regarded as a disease (as the name suggests), in a medical sense, it can also be a disability because of the serious physiological damage it can cause. Physical disfigurement is a visible sign of the disease (disability) and was a reason why many societies in the past shunned people with the disease (disability), as well as those suspected to suffer from it.

In 1957, China introduced the National Plan for Leprosy Control (Leung, 2009). However, the developments of "leprosy control" from that time were uneven across China, and rural populations were particularly vulnerable because of the limited scale of healthcare. Yet, no matter how the government tried to improve public health, social discrimination against Hansen's disease was ingrained in basic aspects of life. People with Hansen's disease were banned from getting licenses to practice in the medical profession; not only that, they were also denied the right to marriage until civil laws were changed in 2001 (Leung, 2009).

In modern Japanese and Korean societies, Hansen's disease is still a condition that is deeply stigmatized, even though effective therapies to treat it have been around for decades (Burns, 2019; Kim 2017). In 1907, the Japanese government introduced the Leprosy Prevention Law, requiring people with that condition but without family to take care of them to be institutionalized (Arlington, 2016). The 1907 law also influenced policies toward Hansen's disease in colonial Korea. The Japanese law was revised in 1931 as the Lifetime Confinement Law, broadening the government's authority to institutionalize a person for life (Arlington, 2016; Burns, 2012). Under the postwar Eugenics Protection Law of 1948, people with Hansen's disease were forcibly sterilized, though evidence suggests that sterilization had been carried out on inmates at institutions even before that law was introduced (Burns, 2019). Japan's 1931 law was finally repealed in 1996, and that marked the start of a new chapter of activism (Burns, 2012). The legal systems of Japan and Korea have started to respond to allegations of past injustices against people with Hansen's disease, and over the years the activist groups have found new political voices to represent their rights (Arlington, 2016; Burns, 2019).

3. Disability and Popular Culture

The representation of disability in modern East Asian popular culture is an important reflection of themes about disability in cultural history. Cinematic and literary genres introduce audiences to disability, and these genres are also sites where stereotypes of disability, and responses to them, are affirmed or challenged. This section looks at some representations of disability and discusses how they are related to their contexts.

Modern Japanese popular culture (film and television) features blind people in roles that "celebrate" their incredible ability and imagines them to be powerful, sometimes clairvoyant, humans who are more capable than sighted people. Miminashi Hōichi (Hōichi the Earless), a blind musician in the Japanese genre of ghost tales, is portrayed as such a "super" blind person. He uses his music to speak to the supernatural world, but because he is blind, he does not know that he is "seen" by the ghostly audience (Prince, 2018). Another famous blind character is Zatōichi, a masterful swordsman. He is depicted as a "super" savior who does not shy away from tough battles to save victims from injustice (Okuyama, 2020). From a historical perspective, many blind people in premodern Japan were musicians, and though there may be similar ideas in popular culture then and now about blind people, blind musicians' genres and performances belong to the contexts of their times (Tan, 2019). The context of premodern (early modern) Japanese society was also favorable to the social organization of blind people (Groemer, 2001; Tan, 2019). Beginning in the Meiji period, the Japanese government focused on raising the level of student enrollment in primary education. As part of this push for education, students with visual and hearing disabilities could enroll in special schools (schools for blind and deaf students), where they were taught academic subjects and skills for vocations, such as music and artisanry, though it is evident that not every child with disabilities could afford an education (Arakawa et al., 1976; Nakamura, 2006).

Modern Japanese popular culture also tackles themes about living with disability. Ōe Kenzaburō, an iconic Japanese writer, uses his works to explore the ups and downs in his relationship with his son Hikari, who has disabilities. He writes about his emotional struggle upon learning that his son could be born with disabilities and about the anxiety of a parent in a society which strives to eliminate disability (Shek-Noble, 2019). Film and literature also examine disability related to Japan's traumatic past. The atomic bombings of Hiroshima and Nagasaki at the end of World War II resulted in countless deaths, injuries, and intense suffering. In postwar works, survivors of those bombings are portrayed as victims bearing war's physical and psychological scars (Shibata, 2019). In Japan's postwar reconstruction period, environmental pollution posed a serious threat to the nation's growth and to human lives. Ishimure Michiko, a writer and environmental activist, uses literature to shed light on industrial mercury poisoning in the fishing town of Minamata. The disease, diagnosed in the 1950s and called Minamata disease, caused serious physical and neurological disabilities among the local residents (Thornber, 2012). The Fukushima nuclear meltdown of 2011 (following the earthquake-tsunami disasters) is a more recent example of environmental pollution in Japanese history. The incident triggered new fears of disability from exposure to radiation, and there is concern that those fears may deepen eugenic views of disability (Mashimo, 2018).

The modern cultural context of South Korea, like Japan's context, tends to highlight that disability is undesirable and diminishes a person's "value" to society. Eunjung Kim's (2017) analysis of disability in South Korea introduces the idea of "curative violence." It is the idea that disability has to be "cured," but "cure" is not what it seems, because it affirms a certain norm that can disrupt the “personhood” of the person with disabilities who is subjected to that treatment (Kim 2017). In recent decades, South Korean filmmakers produced documentaries about disability and gender, challenging the uncritical idea of disability that demeans women with disabilities and limits their prospects of marriage and other assumptions that are eugenically motivated to stop women with disabilities from fully embracing their personal desires (Kim 2017). Novels and films have also highlighted physical and mental violence inflicted upon people with disabilities to “cure” them, unjustified violence that has become an expression of the systemic oppression to dehumanize people with disabilities (Kim 2017).

In modern Chinese popular culture, film opens up new avenues to explore different dimensions of disability. Early postwar films used disability for propaganda to enhance the trope of surmounting disability (seen as adversity) to become “useful” to the nation’s labor force (Dauncey, 2020). People with physical disabilities are cast in roles that glorify the virtue of persevering against disability to benefit the common good (Dauncey, 2020). This ideology of nation before self, or collective effort before individual needs, was central to the Communist government’s powerful mobilization of national spirit. From the 1980s, with the changeover of political leadership and a slow “opening” in the political climate, Chinese films looked beyond predictable, propagandistic plots with disability – though this does not mean that there was broad acceptance of politically sensitive topics. For example, Chinese filmmaker Zhang Yimou’s *To Live*, a 1994 film, can be seen as an allegorical story of China, told through the life of a young woman with hearing and speaking disabilities whose stoic, unbroken silence is a symbol of the nation’s unhealing wound and its unspeakable pain (Riep, 2018). This film was banned in China (Dauncey, 2007). As Steven Riep (2018) explains, later films from the 2000s about disability such as *Breaking the Silence* have focused on the complex parent-child relationship, exploring the choices that a parent has to make in taking care of a child with disabilities. These perspectives, though not always told through the voices of people with disabilities, make disability an everyday experience to which families can relate and humanize people with disabilities in ways that supersede previous propagandistic, nationalistic themes.

Conclusion

This chapter has surveyed disability history through the discussion of science, medicine, law, activism, and popular culture in modern East Asian societies. In each of the societies presented in this chapter, disability was linked to developments in science and medicine. Laws were influenced by those scientific and medical perspectives, and popular culture expressed popular attitudes toward disability. While this chapter uses disability history to draw out some common points about disability in modern East Asian societies, it also reveals that disability history is about diverse perspectives on disability because disability in each society and each culture is unique.

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Transnational History of Disability: Reflections

11

Gildas Brégain

Contents

Abstract

Transnational history is a research perspective that has been widely legitimized and popularized over the past decade, but few disability historians have adopted this approach to date. This chapter aims to review the first transnational studies in the history of disability, highlighting the interest of such a historiographical approach and its benefits and disadvantages. The approach to transnational history continues to be promoted mainly by young historians working in non-Western fields (Eastern Europe, Latin America, Africa) or with a global approach. This innovative historiographical approach generates considerable contributions in terms of knowledge and research perspective. It offers a new reading of history, less national-centric and Western-centric, by shifting the focus to other countries in the world whose experiences in disability public policy must not be ignored by Western historians. It highlights the role of NGOs, private foundations, transnational activist networks, intergovernmental organizations, and new figures (international experts, missionaries, etc.). It thus requires recognition of the foreign contribution to the construction of domestic norms and realities and thus the hybridity of policies pursued at the national level. It also leads to relativizing the singularity of national social movements and national public policies, by pointing out convergences (and divergences) with other

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national realities. The adoption of such an approach also leads to situating local or national experience in a more global historical context (international or regional scale), thanks to a better knowledge of the "field of possibilities" of disability policies at the international level.

Keywords

Transnational history · Entangled history · Global history · Disability · Public policies · Intergovernmental organizations

Transnational history is a research perspective that has been widely legitimized and popularized over the past decade and has been the subject of methodological articles, historical dictionaries (Iriye & Saunier, 2009), handbooks (Saunier, 2013), and specialized journals (*Yearbook of Transnational History*). However, there is no single definition of transnational history among historians. One of its main promoters, Pierre-Yves Saunier, defines it as a history that is focused on interactions, connections, and flows between and across nations over the last 200–250 years and that it is not a history of nations (Saunier, 2013). This historiographical trend has already spread widely among gender historians and childhood and ethnic minority historians, but few disability historians have adopted this approach to date. For instance, the recently published collective syntheses on disability history (Hanes et al., 2018; Rembis et al., 2018; Walmsley & Jarrett, 2019) are organized as juxtapositions of articles with national or local points of view. Only a few authors adopt a resolutely transnational perspective by considering transnational flows and transnational actors (Murray, 2018; McCarthy, 2018; Brégain, 2018a).

The history of medicine and public health already took a transnational turn more than a decade ago. Several works note the influence of international conferences, intergovernmental organizations (Hygiene Organization, World Health Organization, Pan American Health Organization, etc.), or private American foundations in the establishment of policies to combat endemic diseases (polio, leprosy, typhus, etc.) at the international level (Weindling, 1995; Borowy, 2009; Vollset, 2013) or more specifically in some European countries (Piana, 2009; Vargha, 2018), Latin American countries (Cueto & Zamora Mesia, 2006; Palmer, 2015), or North American countries (Inglis, 2014). Similarly, several works document the transnational dimension of the promotion of Atlantic and Latin eugenics (Mitchell & Snyder, 2003; Kühl, 2013; Turda & Gillette, 2014).

The fields of the history of psychiatry and, to a lesser extent, deaf history seem to be ahead of other areas of disability, with the publication of books that demonstrate a progressive "transnational shift" (for psychiatry, see Ernst and Mueller 2010; Ernst 2013, and for deaf history, see Murray, 2007 and Kusters and Friedner (eds.) 2015). Some older works deal with transnational movements for the rights of persons with disabilities (Driedger, 1989; Groce, 2002), but they do not meet all the criteria to be considered as works of transnational history of disability, because they are mostly based on a single archive or on data provided by members of a single NGO and therefore contain many approximations. They are also characterized by a hagiographic tone.

This chapter aims to review the first transnational studies in the history of disability and to shed light on both the richness and benefits of such a historiographical approach and its disadvantages. I will first examine the emergence of this field of research on an international scale over the last decade (I), before highlighting the many innovative results of this research perspective (II). I will then analyze the very complex methodology that needs to be implemented (III).

A Field of Research That Has Emerged Internationally Over the Last Decade

Transnational disability history has been developing since the early 2000s and has become stronger in recent years. This timing can be explained by the conjuncture of two factors: on the one hand, the rise of transnational and global approaches in the historical sciences (stimulated by the internationalization of research) and, on the other hand, the adoption of the *Convention on the Rights of Persons with Disabilities* by the UN in 2006, which led many sociologists and political scientists to point out the importance of the internationalization of public disability policies.

At the dawn of the 2000s, new historiographical trends were emerging, all affirming the need to write histories that go beyond the framework of states and nations: connected history (Subrahmanyan, 1997), entangled history (Werner & Zimmermann, 2003), and transnational history (Iriye & Saunier, 2009). The methodological boundaries of these different historiographical trends have not yet been definitely established. These different historiographical trends seek to distinguish themselves from the older currents of world history and global history, which became institutionalized in the 1980s and 1990s (Maurel, 2009). Those currents claimed to embrace the history of all parts of the world in the case of the former and the study of *globalization* and international issues for the latter. Their work is often criticized for its hasty generalizations, heavy reliance on secondary sources, its Western-oriented worldview, and the fact that they tend to perceive contact between actors in an asymmetrical way (Bertrand, 2013). Some works, however, are more subtle, cover only two or three locations, and attempt to combine games of scales with phenomena of interdependence and connections. Sebastian Conrad proposes, for example, to consider the global history as a perspective, which “is often more a matter of writing a history of demarcated (i.e. non-‘global’) spaces, but with an awareness of global connections and structural conditions” (Conrad, 2016: 12).

An advantage of connected or entangled histories over world or global history is that they do not presuppose that the actors studied are aware of the existence of the world as we currently perceive it and that they perceive their life experiences or problems as belonging to the global scale. The actors studied may also be indifferent to what is happening in other parts of the world (Bertrand, 2013). The writing of an entangled history is demanding in terms of method: it requires adopting a comparative approach that considers the historical variability of the categories studied, as well as the existing variations between the different geographical scales, and adopting a reflexive approach (Werner & Zimmermann, 2003). The connected history approach affirms the need to look at non-Western societies, to play with scales (local, state, etc.), and to highlight the trans-state, inter-imperial, and intra-imperial flows (people, objects, knowledge, or political ideas) and interactions. In line with this approach, Romain Bertrand insists on the researcher's obligation to pay the same attention to non-European sources as to European sources; to reconstruct the framework of thought, discourse, and practices of each actor at the moment when the connections occur; and to ensure that vernacular statements are translated in a comprehensive manner (Bertrand, 2013: 195). He wishes to construct a history "in equal parts" by attributing equal dignity to the points of view of actors from different cultural areas. The comparative work carried out is relatively flexible, allowing for the highlighting of existing discontinuities between societies. This method thus accepts the idea of a possible irreducibility of the historiographies of the societies studied and the absence of common points in their worlds of thought (Bertrand, 2013).

While authors of transnational history often employ a variety of methodologies, they always place particular emphasis on individuals, ideas, markets, and organizations that act between and across nations (Iriye & Saunier, 2009: 20). They focus in particular on the work of intergovernmental organizations, international NGOs, and international scientific networks. Nevertheless, the field of transnational history is not free from legitimate criticism. In fact, it may seem inaccurate to speak of transnational history before the 1960s, given the predominance of the imperial form in Europe until that decade (Cooper, 2010: 190).

The transnational disability history approach is mainly promoted by European scholars (Baár, Brégain, De Schutter, Stoll, Van Trigt, Derksen, Walmsley, Ernst, Cleall, etc.) or North American scholars (Murray, Hanes, Commend, Galmarini) and more rarely by Latin American researchers (Ramacciotti) working on the nineteenth or twentieth centuries. They are generally younger historians working in non-Western fields (Eastern Europe, Latin America, Africa, Asia, Soviet Union) or with a global or imperial approach (Cleall, e.g.). These various researchers analyzed intra-imperial, transnational, and international circulation of individuals (association leaders, intergovernmental experts, missionaries, blind or deaf students, disabled athletes, etc.), objects (prostheses, Braille books, etc.), money, ideas, concepts (the idea of the rights of disabled people, the concept of independent living), and practices such as the segregation of people with leprosy (Edmond 2006). These researchers have examined the exchanges that take place in international conferences and meetings (Séguillon, 2002; Benvenuto & Séguillon, 2014), NGOs of disabled or blind (Galmarini, 2021) or deaf persons (Murray, 2007), the migration plans of some deaf people in the nineteenth century (Cleall, 2016), the construction of international or European disability policies, as well as international or foreign influence on the construction of national social movements or on the construction of national disability policies (Ramacciotti, 2015; Brégain, 2018b; Baár, 2020).

The low interest of historians who specialize in Western countries (i.e., the case of the United States, Canada, England, Australia, or Western European countries) in this transnational approach can be explained especially by two reasons: on the one hand, they do not feel that public policies and the life experiences of people with disabilities in their countries have been influenced by intergovernmental organizations or foreign experiences; on the other hand, they wrongly consider the internationalization of public disability policies to be a post-1980s event. On the contrary, researchers working on non-Western countries are quick to perceive the influence of intra-imperial and international flows of NGOs and intergovernmental bodies at the local level. Does this mean that the transnational disability history would be more relevant in non-Western countries than in Western countries, because of the distinct historicity (and supposed lateness) of their public disability policies? The answer is no, for several reasons. For one, if Western countries have indeed been the promoters of models of public disability policies at the international level, it would be wrong to think that the public policies that have been developed there owe nothing to transnational exchanges of information, at least since the nineteenth century. Many Western actors (doctors, missionaries, nursing sisters, etc.) travelled abroad to visit assistance or care institutions and participated in international conferences. In this way, they built up scientific and social expertise based on a broader horizon of experience than just their national territory. This supranational expertise enabled them to establish their legitimacy at the national level among their peers and with political leaders. Even without going abroad, associations and political leaders often used foreign examples or international texts to develop their projects in the field of disability (new legislation or institutions). The institutions created were generally equipped with new technologies purchased abroad (iron lungs, orthopedic control for cars, etc.). In addition, intergovernmental bodies had a direct influence on the construction of national disability policies since the 1950s, by sending international experts to advise governments or by adopting binding standards (in particular the CRPD and ILO Convention 159, as well as the market opening and austerity policies imposed by the World Bank, the International Monetary Fund, and the European Commission) or non-binding standard (like the Declaration on the Rights of Disabled Persons).

Transnational exchanges (cultural, economic, material, etc.) therefore contributed to transforming local realities on many levels: that of public disability policies, life experiences, but also subjectivity and hopes. Indeed, the transnational circulation of the idea of the rights of persons with disabilities contributed to nourishing and strengthening the idea among persons with disabilities that they hold rights, thus creating a feeling of injustice with regard to a situation deemed intolerable. This circulation transformed partly the subjectivity of individuals, which are fundamental to understanding the dynamics of claims and protests.

Unexpected and Surprising Results, Which Lead to Changing the Way We Look at the Scales of Public Action and Social Movements

This innovative historiographical approach generates considerable contributions in terms of knowledge and research perspectives. It offers a new reading of history, less national centric and Western-centric, by shifting the focus to other countries in the world (particularly those in the Global South and in Eastern Europe) whose experiences in disability public policies must not be ignored by Western historians.

First, it highlights the role of NGOs, private foundations, transnational activist networks, intergovernmental organizations, and new figures (international experts, missionaries, association leaders, migrants, etc.) in the construction of international or regional policies. In my book *Pour une histoire du handicap au XXe siècle. Approches transnationales (Europe et Ameriques)*, I detail how these different actors contributed to the construction of international standards on disability until the 1980s. In the inter-war period onward, many NGOs (Fédération internationale des mutilés, invalides du travail et invalides civils, Association internationale des étudiants aveugles, International Society for Crippled Children, etc.) mobilized themselves to defend the rights of the various categories of disabled persons at the League of Nations and the International Labour Organization, but their mobilization largely failed. After the Second World War, other NGOs (World Council for the Welfare of the Blind; the International League of Societies for the Mentally Handicapped, the Fédération internationale des mutilés, invalides du travail et invalides civils, etc.) had a considerable influence on international disability policies, particularly in getting the International Declaration of the Rights of Mentally Retarded Persons approved by the United Nations, and ILO Recommendation No. 168 on the Rehabilitation of Disabled Persons in 1983. I also pointed to the role of intergovernmental organizations (United Nations, International Labour Organization, World Health Organization) in promoting a North Atlantic project for modernization of rehabilitation from the 1950s onward. This project was characterized by a very comprehensive approach to the question of disability (taking into account all problems, prevention, psychological adaptation, legislation, etc.); the equalization of the rights of all categories of disabled persons and the need to coordinate public disability policies; and a very liberal economic approach to occupational integration (refusal of quotas, creation of sheltered workshops, selective placement, etc.) (Brégain, 2018b). Susanne Commend also documented the participation of Quebec philanthropists in the transnational mobilization in favor of disabled children during the inter-war period, demonstrating the sometimes contradictory aspect of their discourse, which included the promotion of a social conception of disabled children and the legitimization of certain eugenicist values (Commend, 2019). Paul Van Trigt has also shown the growing influence of several NGOs (Disabled Peoples' International, European Disability Forum) on European public action, on the development of the Community action programme for disabled people called Helios I (1988–1991) and Helios II (1993–1996) promoting integration and equal opportunities for disabled people, as well as on obtaining the inclusion of disability in Article 13 of the 1997 Amsterdam Treaty, which stipulates that "the Council (. . .) may take appropriate action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation" (Van Trigt, 2019).

Second, this historiographical approach requires recognition of the foreign contribution to the construction of domestic norms and realities and thus the hybridity of policies pursued at the national level. Katharina Heyer examined how activists in

Germany and Japan were inspired by the US disability rights movement and the Americans with Disabilities Act of 1990 to demand and achieve significant changes in the direction of national policy (Heyer, 2015). She studied the travels of German activists to the United States, as well as the travels of US activists to Japan, which facilitated these transfers. This very interesting work deserves to be put in perspective by two remarks: she focused on American influence (thus prejudging that it is the only foreign influence) and presupposed that there was no transnational circulation of information prior to the American with Disabilities Act (ADA). In my research, I analyzed the way in which experts commissioned by intergovernmental organizations (ILO, WHO, UN) advised the governments of Latin American countries (Argentina, Brazil) on disability issues during the 1950s and 1960s. These experts encouraged governments to coordinate or unify their sectoral policies in the field of disability. They facilitated and participated in the establishment of national rehabilitation centers and reoriented the modalities of occupational integration of persons toward economic liberalization (rejection of the quota principle applied to private companies, creation of sheltered workshops, selection of candidates for professional rehabilitation, etc.). They also promoted a new distribution of medical specialties in the field of rehabilitation (physiotherapists, occupational therapists, physiatrists) and adapted sport. Their intervention favored the partial convergence of national disability policies toward the principles of the North Atlantic rehabilitation project; this convergence was not complete because of the resistance of certain local actors and the low investment of governments. In all three countries, the imperative of coordinating public disability policies led to the questioning of the fundamental characteristics of previously established sectoral policies: the allocation of specific rights to a subcategory (blind, war-disabled, etc.), as well as the existence of administrative bodies responsible for conducting a sectoral policy (rehabilitation, specialized education, assistance for the blind, etc.). Indeed, during the 1970s, there was a partial desectorization of sectoral disability policies, with the disappearance of certain administrative bodies dedicated to a specific disability (war-disabled and blind in Brazil) and the partial disappearance of rights previously given to a subcategory (in particular the blind in Argentina). Other studies have shown that the influence of international organizations on national policies was very heterogeneous and depended on the countries concerned, the local actors, and the times. It often proved to be complex, sometimes very weak and sometimes strong. The historian Monika Baár, for example, has shown that the International Year of Disabled Persons (IYDP) organized by the UN did not result in a strengthening of the British government's action in this field, quite the contrary. The British royal family was very much involved in the organization of the IYPD at national level, but media campaigns were mainly aimed at increasing the resources of large charitable and private organizations (Baár, 2020). British governmental actors were turning away from the concept of independent living to pursue neoliberal policies, rejecting demands for social justice that accompanied the concepts of independent living. They reduced the social benefits of people with disabilities to discourage what they perceived as an attitude of social dependency. They only adopted measures that promoted accessibility and challenged discriminatory attitudes, thus eclipsing the demands of associations in the economic and employment spheres. The measures adopted by the government then led to the aggravation of poverty and the increasing marginalization of persons with disabilities. On the other hand, Sam de Shutter showed that local Kenyan actors did not question the content of the World Programme of Action (1983–1992) put in place by the UN or the universal language used in it (De Schutter, 2019).

Third, the approach of pointing out the convergences (and divergences) with other national realities also leads to relativizing the singularity of national social movements and national public policies, as well as to pointing out the existence of transnational conjunctures (economic, social, political, climatic) in the field of disability history. The study of sources in several countries and the consultation of foreign bibliographies lead us to qualify – and sometimes contradict – the assertions of associative or administrative sources, which generally overvalue the originality and pioneering character of their actions by underestimating the existence of similar projects abroad. By investigating the treatment of intellectual disabilities in France and Germany during the first decades of the twentieth century, Valentine Hoffbeck thus relativized the supposed German advance in their treatment (Hoffbeck, 2016: 114). She showed that the support for German reforms was not universally shared among the French alienists, who were also interested in the experiences of Switzerland, Belgium, and England. She also identified similar dynamics in the two countries (rhetoric of sorting in the treatment of intellectual disabilities, development of a eugenics program, etc.), but Germany stood out radically on an international scale with the introduction of the euthanasia policy in August 1939. Conducting transnational research has led me to observe that the phenomenon of the gradual firing of blind people from teaching posts in ordinary educational institutions and in specialized institutions for the blind observable in the French metropolis during the 1930s (Brégain, 2019) was also observable from 1931 onward in Spain and in 1944 in colonized Tunisia for blind Muslims teaching in Koranic schools. Observing the frequency of this phenomenon prompts the identification of a transnational trend of expelling blind people from teaching posts, linked to the desire to professionalize this specialized education and the gradual devaluation of the teaching capacities of blind people since the beginning of the twentieth century by transnational networks on the education of the blind.

Moreover, Anne Klein has emphasized the importance of the circulation of Western knowledge (notably through the translation into German of the writings of several English and Italian psychiatrists) in the construction of criticisms of psychiatry in West Germany during the 1970s (Klein, 2015). She has therefore shed light on the construction of the anti-psychiatric protest dynamic on a European scale, showing its eminently transnational character. Other research has enabled me to put into perspective the originality of the Anglo-Saxon protest movements of disabled people in the 1970s by insisting on the existence of similar and equally intense protest movements in other countries such as Spain and Argentina, linked to the international promotion of the rights of persons with disabilities, which accentuated the sense of injustice felt by persons with disabilities in many countries of the world (Brégain, 2013). In these cases, it is possible to consider each national experience as a possible variant of the same international dynamic.

Other researchers have studied the borrowings and exchanges between national social movements and national organizations, such as the connections that associations of people with physical disabilities in Hungary had with organizations in other European countries, and with DPI (Baár, 2015), or the support of German disability movements to Nicaraguan disability movements (Stoll, 2015).

Fourth, the adoption of such an approach also leads to situating local or national experiences in a more global historical context (international or regional scale), thanks to a better knowledge of the "field of possibilities" of disability policies at the international level and of the international standards that regulate this field of possibilities. It therefore becomes possible to situate the national or local experience as an innovative policy or one in chronological discrepancy with foreign practices or standards legitimized by international organizations. Let us take the example of the teaching of Braille in specialized institutions, which became widespread in Western countries in the eighteenth and nineteenth centuries and in countries in the South in the twentieth century. This teaching method was legitimized by an intergovernmental organization, the Child Protection Committee of the League of Nations, in 1932 (Brégain, 2018b). The legitimization of this teaching method was accompanied by the marginalization of other experiences of teaching blind children that existed at the same time, such as the teaching of blind children alongside sighted children in municipal public schools in Scotland since the 1870s and France since the 1880s and the oral teaching of blind children alongside sighted children in Koranic schools in Muslim countries (a system that existed at least since the twelfth century). The decision adopted by the Child Protection Committee in 1932 therefore represented a reduction in the field of possibilities in favor of the dominant solution in European countries. Of course, this decision alone does not explain the marginalization of the existing alternative in Arab countries. Other factors contribute to it, including (1) the defense of the system of Braille teaching in specialized institutions by transnational advocacy networks for the rights of the blind; (2) the fact that French people organized a few specialized institutions for teaching French Braille in the empire's territories (like the Algerian colony or Tunisian protectorate) during the first decades of the twentieth century, inspired by the model of metropolitan institutions; and (3) the fact that several dozen blind North African students went to the French metropolis to benefit from schooling in these institutions during the first half of the twentieth century. The latter logically defended this educational modality once they returned to their countries, even after the conquest of independence. More generally, a detailed knowledge of this field of possibilities makes it possible to better understand the perception of local actors of the "modernity," "backwardness," or "anachronism" of their national or local policies.

It also makes it possible to point out the importance of a country's geographical and geopolitical positioning in relation to the different poles of social innovation in the disability sector at an international scale. Esme Cleall has shown the crucial role of the exchange of educational techniques, deaf students, and teachers between the territories of the British Empire, particularly between England, Canada, and

Australia (Cleall, 2015). Maria Cristina Galmarini has shown the crucial role of the All Russian Blind Union in the circulation of knowledge and materials for the blind between the Soviet socialist countries during the 1950s (Galmarini, 2021). In the same way, the geopolitical proximity of some African socialist countries easily explained the choice of new independent governments (like Algeria, Tunisia, etc.) to be inspired by some experiences of the Soviet Bloc countries (Poland, Yugoslavia, etc.) in the field of rehabilitation, like the disabled workers' cooperatives. If circulations of models and experts between socialist countries are perceptible, the attitude of the independent governments of North Africa is characterized above all by their pragmatism. With a great shortage of personnel and equipment, the Algerian and Tunisian leaders sought assistance from many countries, whether socialist or capitalist (United States, Germany, etc.). When asked, the French government refused to send special teachers for the blind to Algeria. Thus, the conquest of independence in Algeria and Tunisia led to the – partly involuntary – break with dependence on France in the field of social protection for the blind, in favor of a multi-polar dependence. On the other hand, the geographical proximity of Mexico to the United States and Canada is a key factor for understanding why Mexico coordinated disability policies in the 1950s by centralizing all the services concerned with disability (including special education) within an administrative department, the *Dirección General de Rehabilitación*, whereas the other Latin American countries did not give impetus to such unification of the rehabilitation and special education sectors until the 1970s. Ultimately, restoring the various possible pasts makes it possible to break definitively with the idea of a linearity of transformations observed on a national scale and obliges us to renounce any glorious interpretation of the national destiny.

Fifth, this historiographical approach also leads to the revision of established periodizations in disability history, by identifying the existence of paradigm shift at the international level and by insisting on the long duration of certain transnational phenomena. It encourages us to take into account not only international conferences, international standards and international programs but also certain national experiences of countries in the North and South as important milestones for understanding disability history at the international and national levels. In deaf history, the *International Congress for the Improvement of the Condition of Deaf-Mutes* held in Milan in 1880 is already well identified as a major turning point because of its role in the international legitimization of oralism and in the discrediting of sign language. Similarly, the first international conference on leprosy held in Berlin in 1897 legitimized the segregation of all leprosy patients as the only means of fighting leprosy. My own research has enabled me to identify several important chronological milestones, including *The Blind (Education, Employment and Maintenance) Act* adopted in England in 1920, a milestone for the cause of the blind at the international level, and ILO Recommendation No. 99 of June 1955, which endorsed a shift toward the economic liberalization of international disability policies under pressure from Anglo-Saxon governments. In fact, during the development of standards on the vocational rehabilitation of the disabled between 1953 and 1955, the United States, the representatives of other capitalist countries, and the employers' representatives succeeded in shifting ILO policies on vocational rehabilitation toward a more liberal economic policy (Brégain, 2019). ILO Recommendation No. 99 legitimated the exercise of a paid professional activity in the context of a liberal market economy. It institutionalized the selective placement of disabled workers in a competitive job market and symbolically depreciated the use of compulsory employment quotas (by submitting its adoption to "specific conditions" and by drowning it in a high number of different possible measures). This recommendation excluded less-productive disabled workers from ordinary work placement and expected them to work in sheltered workshops, as freelance workers, or condemned them to the absence of a remunerated activity. Monika Baár and her team of researchers are committed to demonstrating the crucial role of the International Year of Disabled Persons organized by the United Nations in 1981, a catalyst moment for the politicization of many local and national associations of disabled people (Baár, 2015). The work carried out by this team also leads to reassessing the significance of existing "turning points" in the field of disability at the international level. For example, Paul Van Trigt has shown that during the 1990s there was no "paradigm shift" from a social protection model to an Anglo-Saxon model of civil rights and anti-discrimination at the European Union level, but rather a combination of the two models (Trigt, 2020). It is important to note that most studies continue to legitimize Western-centric periodizations overall, whereas the transnational history approach aims precisely at questioning the legitimacy of Eurocentric chronologies (Clavin, 2010: 627). This persistent flaw can only be overcome once there is a proliferation of detailed studies on the history of disability in the Global South.

Sixth, a transnational approach can lead us to re-examine the originality of the concepts and terms used locally and invites us to denaturalize and historicize socially accepted concepts and point out the importance of linguistic translations. While the French terminology of disability acquired great international renown during the first decades of the twentieth century, the preponderance of the English terminology of disability on an international scale was solidified from the 1950s onward. Thus, while the French concept of *rééducation* was favored by officials of the International Labour Office in the early 1920s, it was then the Anglophone concept of *rehabilitation* (with a distinct meaning and a more economic liberalization orientation) that appeared in the ILO recommendations in the mid-1950s and in UN programs in the sector (Brégain, 2018b). From the Second World War onward, French- and Spanish-speaking actors sought to translate identification (disability, handicapped, etc.) and Anglophone concepts (rehabilitation, etc.) into their languages with varying degrees of difficulty and success. In the Spanish-speaking sphere, disability specialists between the 1940s and 1970s developed multiple proposals for identification inspired by the terminologies disabled (*dishabil*, *discapacitado*) and handicapped (*handicapeado*) or based on other semantic arguments (*menor-válido*, *minusválido*) (Brégain, 2018a).

Seventh, as Ernst and Mueller point out in the introduction to their book on the transnational history of psychiatry, the cross- or transnational approach allows us to cut across and question the relevance of dichotomies such as center/periphery, eastern/western, traditional/modern, and even global/local (Ernst & Mueller, 2010: xi) by highlighting the interactions between these categories and their fluid boundaries. Dóra Vharga, for instance, shows that during the Cold War, Hungarian physicians collaborated with those in the West to find vaccines for the polio epidemic and design appropriate care. In addition, Hungarian hospitals received equipment and vaccines from hospitals in the West and other Eastern European countries (Vargha, 2018). My own research has led me to downplay the supposed "modernity" of the North Atlantic project for the rehabilitation of the disabled promoted by the UN, WHO, and ILO in the 1950s, by giving real legitimacy to other conceptions of progress and other political projects in the sphere of rehabilitation, including socialist projects of rehabilitation and projects from developing countries.

A Complex Methodology to Implement

Historians have used a variety of archives to carry out their transnational research: the archives of international organizations (League of Nations, ILO, WHO, UN, etc.); the archives of international NGOs, diplomatic archives, and administrative and associative archives; and journals of associations, conference proceedings, and also sometimes interviews with administrative officials or activists to supplement the gaps and silences of particular sources, especially in Southern countries like Tanzania (De Schutter, 2019) and Argentina (Brégain, 2018b).

Writing a transnational history has several methodological advantages. By encouraging the researcher to take an interest in different countries and at the international scale, it allows the researcher to identify differences in the historiographical treatment of the same subject from one country to another, to note inequalities in the preservation of archives from one country to another, and to cross-reference data collected in many archives. An archive that is not available or incomplete in one country can be compensated for by discoveries in another country. For instance, the Brazilian parliamentary archives I examined contained many letters from associative, political, or business leaders taking a position on draft laws relating to disability, which was not the case in Argentina. The consultation of international archives (ILO, UNESCO, UN) and some archives of national associations connected in the past to international networks offered great surprises. I have thus found many documents relating to the construction of national disability policies in Brazil, Argentina, Algeria, Tunisia, and Chile in the ILO archives, as well as journals published by associations of blind people in these different countries in the historical collection of the Valentin Haüy Library in Paris.

However, the methodology of transnational history is very challenging to implement. This difficulty is related first and foremost to the complexity of an analytical framework that combines multiple scales and also to the technical, economic, and linguistic obstacles to be overcome, including knowledge of new languages, reading other national historiographies, consulting multiple archives in different countries, significant travel costs, etc. Thus, working on NGO activities during the inter-war period requires the knowledge of several languages (French, English, German) used at international congresses, because communications are rarely translated. Some cases are especially complicated: working on the history of blind people, for instance, entails familiarity with multiple Braille systems (national Braille, abridged, Esperanto Braille).

Moreover, it is not easy to identify all transnational flows (information, mediators, etc.), to pinpoint the regularities in these flows, and to understand their specificities and the issues at stake. It is, for example, difficult to understand the stakes of these journeys for the individuals concerned and to grasp their impact on their life trajectories and ideas. Ideally, the individual's frame of mind, discourse, and practices should be reconstructed at the time when they meet other actors abroad, while giving equal dignity to the points of view of actors from different cultural areas, as recommended by Romain Bertrand (Bertrand, 2013). The social origin, personality, professional trajectory, personal and professional strategies, and multiple loyalties of individuals circulating within the imperial or international arena, or working in international organizations, should also be studied. Indeed, these actors often retain multiple loyalties (with a government, a professional or charitable association, a foundation, the Church, etc.) that influence the content of their actions and the documents they write.

Efforts must also be made to spatialize and temporalize transnational flows to avoid portraying a linear and homogeneous diffusion of ideas and individuals in space. To give meaning to the multiple flows of information observable on an international scale, historian Pierre-Yves Saunier suggests reconstructing circulatory and connective regimes or configurations, "conceived as the regularities that frame the possibilities of actors, contents, directions and impacts of flows" (Saunier, 2010: 152). The historian must try to grasp the attempts by certain actors to put in order the space of flows and the way in which these flows constitute resources for local actors. The aim is to identify "the lasting interactions between mutually identified actors who take part in these flows, whether in the form of competition, cooperation or hierarchy" (Saunier, 2008: 16). From the time of their creation, intergovernmental bodies have played a considerable role in the organization of these flows (information, experts, scholarship holders, equipment). It is their administrations that determine, alongside the directorates of the main NGOs in the sector, the circulation regimes in the disability field.

It is necessary to be cautious in interpreting these transnational flows and not to overestimate their importance in shaping national realities. Sometimes a local phenomenon has no connection with the outside, and the transnational approach is not relevant in this case (Conrad, 2016: 16). Some transnational flows had a strong impact on public policies, on social movements, and on individual or collective memory, while others did not. One of the main reasons for weak influence is the complex process of appropriation of ideas from abroad by local actors. This phenomenon of appropriation "refers to the ways in which the receiving civilization or groups transform and distort inputs to adapt them to their own cultural context and social needs (Ruggiu, 2007)." One should not neglect to consider the potential resistance to transfer from one group to another or the disconnections that result from linguistic difficulties, ideological differences, cultural discontinuities, or pragmatic disagreements. The major challenge is to identify the social and political status of those who take up these ideas or reject them, since their status largely determines the future dissemination of information.

The overvaluing of the information that circulated internationally sometimes leads researchers to make three mistakes. The first is to consider human rights enshrined in international texts as objective and legitimate rights, as universal concepts, when in fact they are social constructs that should be historicized and denaturalized by identifying the conflicts and agreements that have presided over the determination of these rights and by identifying the limits of the universalist claim of these concepts by exposing other conceptions of human dignity. The second is to consider that the local reality of disability must be studied exclusively or primarily through the lens of these international texts. The application of international texts is therefore considered logical and necessary. There is then a great danger of interpreting "everything else as lack, failure or distortion" (Cooper, 2010) and thus of taking a restrictive and simplifying view of reality. This bias is perceptible in many studies, including my own to some extent. While I have questioned the extent to which international disability policies apply to Argentina, Brazil, and Spain and why, I have also interpreted certain local practices that were unrelated to international standards, such as begging and street selling, as practices that were in discordance with international standards (Brégain, 2018b), thus positing them as symbolically inferior to these practices. Dipesh Chakrabarty insists on the need to read this "lack" and inadequacy differently, by interpreting it as creativity (Chakrabarty, 2009: 77). He also suggests revealing the "ambivalence, contradictions, use of force, as well as the tragic and ironic aspects" of this imposed modernity (Chakrabarty, 2009: 89), in order to be able to imagine "the radical heterogeneity of the world" (Chakrabarty, 2009: 92). The third is to have a vision centered on state policies and their collaborators (private associations), unwittingly neglecting the study of the alternative practices of organized groups that act without collaborating with the state, including indigenous communities or certain religious groups.

Moreover, one should not only focus on flows but also question the absence of circulation of certain individuals or elements; the political, economic, or social reasons for this lack of contact with the outside world (especially in the case of authoritarian regimes); and their consequences. Transnational history invites here to pay attention to the material aspects of disability history and to the transnational circulation of new technological objects (Braille printing machines, Braille tablets, adapted car, cochlear implants, etc.). During the 1950s, the manufacture of cars with orthopedic controls was concentrated in Germany, and their price was very high abroad because of the import taxes at that time. The autarkic economic policies of the Franco regime explain why these cars were not imported from Spain at least until the early 1960s, even though Germany was geographically close. The hermetic nature of Franco's regime is also reflected in the lack of change of terminology related to disability: for example, the term *inválidos* (invalid) was retained by associations under state supervision (*Asociación Nacional de Inválidos Civiles*) until the mid-1970s. On the other hand, although geographically distant, associations imported cars with orthopedic controls into several Latin American countries from the late 1950s onward. Because the high price of these orthopedic orders (including taxes) hindered the purchase and use of these adapted cars, Latin American association leaders mobilized politically to obtain exemption from import taxes for these cars throughout the 1960s and 1970s.

The historian interested in transnational dynamics can quickly think of elaborating international comparisons with a multitude of countries from the very rich international archives, digitized sources available online, and secondary sources. This is a temptation to which the historian can easily succumb, but one that I think it is best to avoid, as these different bodies of sources are generally too limited to identify with precision and nuance the characteristics of each national case. It is essential to make systematic visits to the countries under study to search local archives and the local press or to conduct interviews. This makes it possible to broaden the range of sources consulted and to better understand the local context of knowledge production (Ghobrial, 2019: 11). This broadening of sources nevertheless causes another problem: the scope of the subjects to be studied and the considerable quantity of sources (primary and secondary) sometimes oblige the historian, for reasons of time and limited publication space, to synthesize all the data collected and interpreted critically without systematically explaining the conditions of production and transmission of each source.

Another pitfall of most transnational disability history work – including my own – deserves to be pointed out and explained: the scant attention paid to intersectional issues, except in Esme Cleall's works about the British Empire (Cleall, 2015; Cleall, 2016). This lack of attention seems to me to be linked to several converging factors: the enormous quantity of sources to be mobilized in order to construct a transnational history and the limited presence of clues and sources for studying these intersectional issues in the archives of intergovernmental organizations. Let's take the case of the research I conducted on the construction of international disability policies from the 1920s to the 1980s. The international sources mobilized allowed me to briefly mention the mobilizations for the rights of women with disabilities that emerged during the 1970s, but the over-representation of men among the leaders of NGOs and international civil servants gives the impression that the struggle and action for the rights of people with disabilities at the international level remained a male affair until the mid-1970s. I unintentionally made two mistakes: I did not try to explain this confiscation of decision-making power in the field of disability by men; and I unintentionally overlooked the existence of certain women's movements of the inter-war period, which had not succeeded in structuring themselves sufficiently at the European level to challenge the intergovernmental organizations. The sources mobilized at the time did not allow me to have knowledge of them; it is the research in local associative archives that allowed me to bring to light the existence of a transnational network of blind feminist women, visibly structured around two figures, the German Hildegard Mittelsten Scheid and the Swiss Marguerite Schaffer. Indeed, German-speaking blind women organized themselves into an association and demanded, as early as 1913, that they be able to benefit from domestic education in institutions, as well as work opportunities for blind women, and the creation of single-sex homes (Mittelsten Scheid, 1927). Similarly, I have not discussed the interaction between the disability rights and anti-racist movements in my book, as the sources consulted in the archives did not lend themselves to this. Fortunately, I believe that this partial obscuring of other features of social differentiation (gender, ethnic groups, social classes, age, etc.) in the transnational disability history literature is only temporary, as the growing body of work on this topic now provides a comprehensive framework for understanding that allows for more focused studies on these issues (as, e.g., around disabled refugees, etc.).

Another major difficulty in carrying out transnational history work is grasping the nuances of the terminology used in foreign countries, which is necessary to better contextualize the transfer of information. When a study covers several countries, the researcher must generally master several languages. When the study concerns a single country, the researcher may sometimes make mistakes by copying the foreign terminology used in the sources consulted without critical distance. For example, Jan Stoll states in his article that a Nicaraguan organization is called Organización de Revolucionarios Dehabilitados, probably trusting a wrong German source, since the term dehabilitados does not exist in spanish, while the term deshabilitados was used from the 1960s onward by some authors as a translation of the English-speaking concept of *disabled*, thus proving a strong Anglo-Saxon influence on rehabilitation science in this particular organization. In addition, there are the difficulties inherent in translating historical writing into different languages already pointed out by Waltraud Ernst and Thomas Mueller (Ernst and Mueller, 2010, p. xii). In the case of transnational studies based on international and national sources, there are the almost insoluble problems of how to be faithful to the terminology of the national original sources (e.g., the term *lisiado* used in Argentina at the end of the 1940s, which literally translates in English as “crippled”); how to be faithful to the terminology used at the time in the English-speaking sphere; or even how to be faithful to the terminology used in international texts at the time (*handicapped* or *invalids* and their Spanish translation *impedidos and inválidos*).

These multiple difficulties in adopting a transnational perspective lead us to recommend two possible types of transnational studies:

(1) Transnational studies focused on two or three countries. This perspective is very enriching because it opens up a horizon of experiences, historiographical traditions, and vast sources that oblige the researcher to be very reflexive in the construction of the object of study and the chronological boundaries. However, it also forces the researcher to compare national cases, to study the historical variability of the categories studied in each country, while analyzing the relationships, the multiple transfers of information, and the resistance to transfers between these countries. As a result, this perspective proves to be very complex to implement and requires many years of research. Above all, it is difficult to construct a coherent chronological breakdown common to several countries, due to the multiple temporalities to be taken into account. Other difficulties may arise, such as determining the representativeness of the phenomena studied at the level of each country and the “difficulty of establishing the simultaneity or anteriority of phenomena observed in both countries, with a view to cultural and scientific transfers” (Hoffbeck 2015: 43).

(2) Studies based on a single territory, an object, a small group, a single individual, or a short period of time, with a transnational approach (but without necessarily

taking the state framework as a reference), following the principles of “global” or transnational micro-history (Bertrand & Calafat, 2018; Ghobrial, 2019; Vries, 2019). This research perspective requires the researcher to be attentive to small details or clues, to the diversity of circulation that may be seen, to the criticism of archives, and to foreign terminology. This transnational micro-history is concerned with the singularity of the historical contexts (local, regional, national, and international contexts) and may lend itself more to a social history approach, because it restores the framework of thought of the actors and their agency, wishes, and uncertainties and describes their concrete social practices. Rather than focusing on exceptional cases or fascinating personal trajectories, this micro-history is based on “an affinity for methods geared towards experimentation – whether it be the cutting out of the object observed under the magnifying glass, the questioning of major explanatory paradigms, close dialogue with the social sciences, narrative inventiveness, attention to the production of social categories and contexts, or reflexivity with regard to the focal points of analysis” (Bertrand & Calafat, 2018: 10).

Aude Fauvel’s study of the case of Baron Raymond Seillière is a good example of this approach. It analyzes the trajectory of this wealthy individual in France and the United States. Baron Seillière was interned in one of the best French asylums by his sister. He paints a very negative picture of the care he received from the French alienist, a story that was quickly publicized in British, American, and French newspapers (Fauvel, 2010: 213). While doctors such as Charcot considered Seillière to be suffering from “ an excited temper ,” Raymond Seillière admits that he was only “ an eccentric man, but not pathologically so .” The American embassy quickly intervened to demand Seillière’s release. The “Seillière Case” contributed to the international media campaign against the abuses of the alienists and encouraged psychiatrists and administrators of institutions to make international comparisons on how to deal with the mentally ill people.

Conclusion

The approach of the transnational disability history invites the researcher to observe transnational flows, transnational networks, transnational dynamics, international norms, conjunctures in transnational economics (economic crisis, etc.), politics (wars, etc.), and health (pandemics) that can influence the living conditions of people with disabilities in the various regions of the globe. This approach offers a new reading of history, less Western-centric, which considerably renews our understanding of the construction of international disability policies, of movements for the rights of persons with disabilities, and of the hybrid nature of national disability policies. The transnational history of disability is an extraordinary field to explore, with many discoveries still to be made about disability rights movements, about the transnational construction of categories of disability, about colonialism and imperialism, about the challenges of citizenship, as well as about the migration of disabled people.

The adoption of this transnational perspective does not prevent the researcher from conducting intersectional research, but it does make it difficult to take into account at the same time all the other factors of social differentiation (gender, ethnic groups, social classes, age, etc.) as a local historical study allows. The researcher must therefore always bear in mind that the transnational history he or she is writing will always be fragmentary, but that he or she must strive to uncover these intersectional issues, to make visible the life experiences of people with disabilities in all their diversity, in order to avoid reinforcing all kinds of prejudices (gender, ethnic, etc.).

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Part III

Disability Paradigm Shifts

Disability Paradigm Shifts: Models, Perspectives, and Philosophical Orientations Driving Change – Introduction

12

Anna Lawson and Margaret Wazakili

Contents

Abstract

In this chapter, we introduce Part III of the handbook and contextualise the chapters within it. We begin by explaining the overall aim of the part. Put simply, this is to explore and highlight the connection between positive social change and ways of thinking about and understanding 'disability'. We then introduce two 'models', or ways of understanding disability, which have had a particularly powerful impact on generating and informing initiatives to enhance full inclusion and participation and to reduce disability-related oppression in all its forms. We then introduce and contextualise three chapters in this part which critically reflect on how these models have been put to work in particular places and particular times. This chapter closes with some brief concluding reflections.

Introduction

In this section of the *Handbook of Critical Disability Studies*, authors explore how different ways of thinking about and understanding "disability" and social responses to body/mind difference have driven and continue to drive change, and the demand for change, in areas such as professional practice, law, and policy. Shifts in how "disability" is modeled or understood have played a key role in the development of

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both Disability Studies and disability politics. They have also influenced, and continue to influence, the substantive content of law and policy as well as the process through which it is developed (▶ Chap. 14, "Disabled People's Mobilization Around a Human Rights Approach to Enhance Their Participation in Law and Policy Making in Iceland," by Love and Traustadóttir, this volume).

The social model of disability and the human rights model of disability are two examples of ideas which have proved particularly influential in mobilizing and collectivizing political action, reorienting perspectives, shifting paradigms, and bringing about social change. While they have each been influential across the world (Sansome, 2020), there has been variation – sometimes quite considerable – in their interpretation, application, and impact. Some of this variation is apparent from the different histories, experiences, and challenges discussed in the five chapters which follow – each of which is grounded in a particular geographical, cultural, and socio-political context.

Chapters in this section will engage with these different "models" or ideas, exploring how they have emerged and been put to work in different countries and their role in bringing about positive change in the lives of disabled people. Although questions of how these models relate to each other are interesting and important (Levitt, 2017; Lawson & Beckett, 2021), such issues lie beyond the scope of this section. While the starting-point for the chapters is abstract – an idea, model, or perspective – each chapter demonstrates how making these ideas work to support the goal of improving the lives of disabled people demands strategy, pragmatism, and, very often, compromise. The ways in which these ideas or models are used in practice by change-makers is therefore a central concern of all five chapters.

The idea of the social model of disability originates in the disabled people's movement (Union of Physically Impaired Against Segregation/Disability Alliance, 1976, 3). The idea of the human rights model of disability is born out of disability politics and the work of disability activists working in the human rights system (e.g., UN Committee on the Rights of Persons with Disabilities, 2018, para 9; Degener, 2016; Degener, 2017a, 2017b). Such ideas are valued among those working at the coalface of disability activism for their potential to make a difference in practice. Thus, Mike Oliver (2004, 31) – who first coined the phrase "social model of disability" (1981, 31–32) – described the social model as a "practical tool" and Degener (2016, 46–47) – who played a lead role in the development of the human rights model – described it as a "roadmap" for achieving disability rights. Disability activists have at times become exasperated by academic critique and its potential to complicate, confuse, and thereby undermine political struggles for relevant positive social change. For example, writing from outside the academy, Richard Light (n.d.) once observed that:

> It is becoming increasingly clear that one of the key issues in disability activism – the Social Model of Disability – is subject to repeated attacks, particularly within the academic community. What is equally clear is that much of the 'bad press' has been prompted by interpretations of the social model that many of us would find particularly strange. . . . We believe that it is time for disabled activists to remind academics that the social model originated with us, and that we still have use for it!

Similar frustration has also been expressed by disability activists working within academia. For example, in 2013 (1204–1206) Mike Oliver wrote that "... despite the impact this model has had, all we now seem to do is talk about it" and "the talking has to stop."

Concerns such as these will of course be taken seriously in Disability Studies scholarship, which is closely connected and intertwined with disability activism and disability politics. Nevertheless, critical reflection on how disabled people have put different ideas and models of disability to work in different places and at different times – to achieve the same broad goal of reducing the oppression, inequality, and marginalization experienced by people with impairments or body/mind differences – undoubtedly has valuable contributions to make both to academia and activism. The purpose of these chapters is to reflect on how the social and human rights models have been put to work in the mobilization of disability activism, the legal recognition of disability rights, and the shaping of positive change. To remain useful and relevant, such models or ideas need to be sensitive to the particular time and place in which, and purpose for which, they are being put to work (Levitt, 2017, 589). Accordingly, diversity of context and country has been an important factor in the selection of the chapters that follow.

The first of the remaining five chapters in this section, by Miro Griffiths, focuses on the social model of disability and its power as a call for change, focusing on its emergence and continued importance in the UK. Griffiths makes a convincing case for the social model's continued centrality to understanding and politicizing experiences of disablement and to building solidarity and consensus among activists.

The second of these chapters, by Laufey Löve and Rannveig Traustadóttir, concerns the application of the human rights model in Iceland. It reflects on how disabled people's organizations drew upon this paradigm to persuade government to change the process of relevant law and policy-making. More particularly, the authors explore the use of the human rights approach reflected in the UN Convention on the Rights of Persons with Disabilities (CRPD) to persuade government to more meaningfully consult and engage with disabled people's organizations – an engagement which in turn influenced new disability-related legislation in significant substantive ways consistent with the human rights model.

The third chapter, by Sanjay Jain, provides a fascinating analysis of how social and human rights models of disability have been referred to and used by judges in the context of disability rights cases. He considers how these models, or approaches to disability, underpin key examples of progressive case law. Explicit references to them have increasingly been made by judges in such cases, particularly since India's ratification of the CRPD and the enactment of the Rights of Persons with Disabilities Act 2016. While constitutional and statutory law tend to be the primary focus of disability rights activists seeking positive legal change, Jain's chapter highlights the important role that can also be played by judges and the actual and potential influence of the social and human rights models of disability in this context.

The fourth chapter, by Yi Huang and Bo Chen, again focuses on the human rights model but this time in a very different context – the People's Republic of China. Using several inclusive education case studies, it explores and critiques the power of the human rights approach, in a non-Western and non-liberal regime, to add strength and momentum to civil society initiatives for positive change.

The focus of the final chapter, by Diana Msipa and Paul Juma, extends beyond developments within particular countries to a more regional multinational level. It provides insightful reflection on the relationship between the social and human rights models of disability and the emergence of the Disability Rights Protocol, adopted by the African Union in 2018. The adoption of that Protocol, they argue, was driven in part by calls of disabled people in Africa for greater recognition of the social and human rights models of disability. As Msipa and Juma make clear, while global developments (particularly those associated with the CRPD) were influential in the emergence of the Protocol, the unique lived experience of disabled people in Africa shaped the emergence and content of the Protocol in distinctive ways.

In conclusion, the focus of this section is the translation of ideas into practice. The social and human rights models of disability are two ideas which have proved, and continue to prove, particularly useful to disabled people and their allies, but much work remains to be done to achieve the positive social change that is still so clearly needed. As the chapters in this section demonstrate, that work can take many forms. What is critical is that there is no one template and no single or right way of putting these ideas to work. There must be adaptability so that strategies and solutions can remain responsive to the particularities of the context – temporal, geographical, political, cultural, and social – in which the relevant social change is being sought. Ideas such as these have and will prove important to achieving positive social change for disabled people around the globe.

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UK Social Model of Disability and the Quest for Emancipation

13

Miro Griffiths

Contents

Abstract

The route to disabled people's emancipation is complex and requires a critique of how the organization of the social world contributes to disabled people's marginalization. To achieve this, contingents within disability activism have focused on identifying the material and discursive arrangements that (re)produce disabling barriers for people with impairments, health conditions, and diagnostic labels. Activists articulate micro-, meso-, and macro-solutions to destabilize the arrangements that perpetuate disabled people's marginalization and implement alternatives to support disabled people's participation in society. For disability activism and disabled people's social movements to operate effectively, activists need to maintain solidarity. In the UK, activists and social movement members have attempted to build a consensus through determining what disability is and how it is experienced (Griffiths, 2019). This has led to the creation and adoption of the social model of disability – an interpretation that positions disability as an oppressive force, which is imposed on people with impairments through the organization of society (UPIAS, 1975).

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Disability activism · Disabled people's social movements · Emancipation · Resistance practices · Social model of disability

Introduction

The route to disabled people's emancipation is complex and requires a critique of how the organization of the social world contributes to disabled people's marginalization. To achieve this, contingents within disability activism have focused on identifying the material and discursive arrangements that (re)produce disabling barriers for people with impairments, health conditions, and diagnostic labels. Activists articulate micro-, meso-, and macro-solutions to destabilize the arrangements that perpetuate disabled people's marginalization and implement alternatives to support disabled people's participation in society. For disability activism and disabled people's social movements to operate effectively, activists need to maintain solidarity. In the UK, activists and social movement members have attempted to build a consensus through determining what disability is and how it is experienced (Griffiths, 2019). This has led to the creation and adoption of the social model of disability – an interpretation that positions disability as an oppressive force, which is imposed on people with impairments through the organization of society (UPIAS, 1975).

The social model of disability (social model) remains integral to and within the organization of disability activism, as well as the progression of disability politics in the UK. The model's significance is identified within the strategies of Disabled People's Movements (Griffiths, 2020; Hasler, 1993), is centralized within the work plans of Disabled People's Organisations (DPOs) across the globe (Berghs et al., 2016; Hallett, 2015), and is referenced by public bodies and government departments in developing disability policy (Department for Work and Pensions, 2019). Within academia, the social model continues to be a focal point within Disability Studies literature – offering an ontological position to understand how people with impairments and health conditions experience disability. The interdisciplinary nature of Disability Studies (Oslund, 2015) provides scholars, who are often engaged in social sciences, law, humanities, and engineering, with opportunities to contribute research findings to disability activism. Such contributions can range from producing research to inform activist strategies through to scholars participating in activist networks and disabled people's social movements.

The chapter begins with an overview of the social model and describes its origins within the UK. It charts the activities of several key disabled activists committed to self-representation and who were instrumental in positioning disability as a consequence of societal organization. Attention is given to the fundamental principles outlined by the Union of the Physically Impaired Against Segregation (UPIAS), which are considered to underpin the social model of disability. The chapter then explores the social model's historical and contemporary relevance to disability activism and disabled people's social movements. This is focused primarily on the UK context; however, the social model's significance on an international level is acknowledged. Exploring the model's relevance is categorized into three areas: individual liberation, collective political action, and organizational policy influence. The final section provides commentary on the model's significance within future mobilizations of disability activism. This reveals possible routes toward ensuring that the social model continues to generate resistance-based practices, which are necessary for progressing disabled people's emancipation. Here, consideration is given to how the social model can facilitate meaningful and accessible participation of newcomers and existing, peripheral members of the UK Disabled People's Movement.

The chapter uses terminology often employed within a UK context. "Disabled people" is preferred over persons with disabilities, as the former places emphasis on disabling conditions and arrangements that are imposed – unnecessarily – on individuals with impairments and health conditions. This is of strategic importance to UK disability activism because the focus is on ideas, practices, and configurations that perpetuate disabled people's marginalization. Similarly, terms such as mental health conditions are used in order to reflect activist identities in the UK. Finally, the notion of resistance is employed throughout the chapter. This is done to frame the ideas and practices emerging from disability activism as acts of resistance. The chapter draws from Foucault's (1997) assertion that resistance provides space to remake the social world and introduce alternatives to the present. Power is considered relational and resistance remains a possibility. Disabled activists have the capacity to instigate practices that resist disabled people's current position in society and can introduce preferable futures that are predicated on inclusion and accessibility.

Origins of the UK Social Model

Disabled people's representation is littered with examples of violence, precarity, and an overreliance on charitable interventions (Hughes, 2015). Individuals and collectives have established resistance practices to challenge the segregative initiatives and deprivations experienced by the disabled people's community – all the while against the backdrop of undermining disabled people's contributions and questioning the value and worth of their existence. Hanes et al. (2018) provide a comprehensive account of the histories of disability – with particular reference to social policies, welfare regimes, education, and labor market access. To understand the origins of the UK social model, it is necessary to focus on the position of disabled people, and policy interventions, post-Second World War. As argued by Barnes (2012), widespread escalation of global violence and conflict resulted in considerable numbers of injured civilians and military personnel returning with health needs and support requirements. In addition, progress in medical treatments and increasing affluence improved life expectancy for disabled and older populations. Policy interventions and welfare regimes were required to "protect" disabled people.

Protection measures were, arguably, a continuation of the tolerated segregative and paternalistic interventions witnessed before the Second World War. The majority of disabled people were still incarcerated within institutions, against their will, and isolated from communities beyond the entrance door of the residential care facilities. Others were confined to assistance from family units, which restricted choice and control over daily life. Disabled people struggled to access, and survive on, social security cash payment. People who were unable to work found it difficult to contribute to insurance schemes (Stone, 1984). This reinforced disabled people's position as passive and dependent, in need of guidance and direction from health and care professionals (Kelly, 2011). Throughout the 1960s and 1970s, disabled people resisted in the hope of articulating alternative approaches to describing and understanding disability, as well as destabilizing current approaches to addressing the "problem" of disability. Groups emerged, which focused on different aspects associated with disabled people's participation in society. Megan du Boisson and Berit Thornberry established the Disability Income Group (DIG), with campaigns surrounding the categorization of "civilian disabled" and the provision of cash benefits and mandatory basic services to meet disabled people's needs (Millward, 2014). Emphasis was placed on the creation of a National Disability Income to respond to the poverty conditions experienced by the disabled people's community. Subsequently, the Disability Alliance (DA) was formed in 1973, which brought together organizations of and for disabled people engaged in reforms to social security and welfare provision.

With dissatisfaction surrounding the limited focus on incomes, some members of the DIG splintered and organized around a central exploration of disability as a form of social oppression. For Paul Hunt (1966), there was a need to highlight how disabled people experienced marginalization through their relations in contemporary society. Hunt argued that disabled people were relegated to occupying positions of tragedy, inadequacy, deviance, oppression, and illness. There needed to be a critique of the current policy initiatives, welfare programs, and service provision in order to understand these positions further and identify how they impacted disabled people on a daily basis. Furthermore, there was a need to reject the narratives perpetuating marginalization, such as the tragic assumptions that surround impairments and the importance placed on charity to alleviate presumed suffering. Hunt and others (Finkelstein, 2007) were concerned with disabled people's isolation and the impact this had upon the development and sustainability of social relations (such as within the family, employment, and local community).

These ideas brought attention to the way disabled people experience discriminatory social relationships. According to Townsend (1966), this reconditioned the understanding of disability through a new, social interpretation. Resisting notions of passivity and dependency, disability was to be understood as a consequence of how the social world is organized. Disabled people were encouraged to challenge the practices, attitudes, and arrangements that restricted their participation in society (Hunt, 2019).

This inspired new forms of activism and the collective organization of disabled people. UPIAS was formed in 1972, occupying a political platform that challenged the ideas of DIG and the DA more broadly. Subsequently, the publication of UPIAS' Fundamental Principles of Disability (1975) presented a concise articulation of disability as a form of social oppression:

> "In our view, it is society which disables [. . .]. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. It follows from this analysis that having low incomes, for example, is only one aspect of our oppression. It is a consequence of our isolation and segregation, in every area of life, such as education, work, mobility, housing etc. [. . .] For us as disabled people, it is absolutely vital that we get this question of the cause of disability quite straight, because on the answer depends the crucial matter of where we direct our main energies in the struggle for change. We shall clearly get nowhere if our efforts are chiefly directed not at the cause of our oppression, but instead at one of the symptoms. [. . .] We see the essential task [. . .] as that of helping disabled people to organise together to take a more active part in struggling for the changes in society which ensure that we are brought into the mainstream of life, rather than being excluded." (p. 3)

There are three important points to draw from this articulation of disability and which remain significant to the contemporary activities and strategies within disability activism. Firstly, it creates the distinction between impairment and disability. Impairment, and by extension health conditions and diagnostic labels, cannot justify the exclusion, isolation, and oppression experienced by individuals and groups. Discursive and material aspects, located within the various arrangements that constitute society, produce the conditions that render people with impairments isolated and excluded from participating in their communities. For Light (2010), this distinction shifts disability to be understood in terms of restrictions imposed upon people. Secondly, this articulation of disability places emphasis on identifying and responding to the barriers within the arrangements that constitute society. Instead of a focus on presumed limitations and losses within bodily functioning and cognitive processing, attention turns to the barriers that emerge through political, economic, social, cultural, technological arrangements and so on. These barriers become the focus of disabled people's resistance practices (Beckett & Campbell, 2015). Thirdly, it promotes the importance of meaningful engagement with disabled people and their self-representation. Aspects that are imperative for progressing disabled people's inclusion within society. A feature of this articulation of disability is the commonality identified through the exclusion and isolation experienced by people with various health conditions and impairments. Disabled people, collectively, have organized themselves to shape policy development (Thill, 2015) and create agendas and strategies that facilitate activist mobilization (French & Swain, 2011).

It is important to distinguish between UPIAS' interpretation of disability as a form of social oppression and its formalization by Oliver (1990), who coined the term "the social model of disability." The former illustrates disabled activists collaborating to understand disabled people's position in society and articulate an approach to bring about social change – an interpretation that was developed by, and for, disabled activists. The latter was introduced as a contribution to the existing literature on the sociology of disability and to aid knowledge transference in learning environments. This chapter is concerned primarily with the social model as articulated by UPIAS and its significance to disability activism. Focus now turns to the application and significance of the social model within historical and contemporary forms of disability activism.

UK Social Model and Disability Activism

As noted in the previous section, social model principles were instrumental to disability activism mobilization in the UK and internationally. As activist networks organized across the globe, and expanded into disabled people's social movements, the social model was considered a central tenet of disability activism (Hasler, 1993). The model facilitated a growth in disability politics, as disabled people identified a shared commonality in their experiences of marginalization and injustice. Solidarity was based on identifying, and challenging, the arrangements within society that (re) produce disabling barriers.

Globally, the United Nations (2004) incorporated the social model into its International Norms and Standards relating to Disability. Its analysis originated from a social model perspective and explored the various forms of discrimination and exclusion experienced by disabled people. It was concluded that disabled people experience violations and, to address this, legislation and policy processes should incorporate a human rights framework. Discussions continue on the significance and application of the social model within United Nations activity, particularly with regard to the Convention on the Rights of Persons with Disabilities (UNCRPD). Clough (2015) argues that UNCRPD harnesses the social model to promote responsive state and judiciary approaches to disability and social justice. Disabled activists, and their organizations, can use such insights as a way to resist the narrow, medicalized perspectives imposed on people with cognitive impairments. It can lead to disabled activists articulating possible and preferable alternatives to supporting disabled people throughout judicial proceedings. For Degener (2016), the social model was pivotal to negotiations over the drafting of the UNCRPD. This reflects the model's significance among disabled activist networks throughout the globe and serves as a tool to reform social arrangements throughout society. Although Degener proposes moving beyond social model application toward a human rights model, others (Harpur, 2012; Kayess & French, 2008; Lawson & Beckett, 2020; Traustadóttir, 2009) acknowledge its significance within and beyond convention drafting. Lawson and Beckett (2020) suggest the social model served four purposes during the drafting of the CRPD: as a reference point to understand disability, to describe disability, as a vision to promote inclusion and equal opportunities, and to build solidarity.

These four purposes are reflected often in DPO work plans and strategic objectives. The European Network on Independent Living is a DPO that advocates and lobbies for de-institutionalization, provision of personalized support, and disabled people's active participation. The Network's statement on appropriate terminology (ENIL, 2021) incorporates the social model in its attempt to build coalitions with

DPOs across Europe. The social model is embedded within its contributions to intergovernmental action plans and policy briefings, such as the European Commission Social Pillar Action Plan on Disability 2021–2030 (ENIL, 2020). Here, the social model is articulated as an approach to differentiate the Network from other disability-related European organizations – notably organizations not controlled by disabled people. The model is used to illustrate grassroots mobilization of disabled activists and to emphasize self-representation. In addition, it is applied to improve transferability of conceptual principles (e.g., choice, control, self-determination) into specific actions and practices. Furthermore, the Youth Network facilitates young disabled people's participation in projects across areas of employment, politics, sexuality and relationships, mental health, education, and the pursuit of independent living. Throughout its work, the social model is referenced as integral to improving youth participation within disability activism across Europe (ENIL Youth, 2015). Manuals developed for increasing participation referenced the social model as an essential tool to build solidarity among disabled young people across European states (Todd et al., 2012). Scholars and activists continue to debate social model application beyond the UK context; Barnes and Mercer (2005) provide a comprehensive collection of activist and academic writings on how the social model impacts disabled activist mobilizations, rights-based agendas, and social policy discourse across Europe and the majority world.

It is important to consider the social model's historical significance to disability activism in the UK. The British Council of Disabled People (BCODP), later renamed United Kingdom's Disabled People's Council, was established in 1981. BCODP represented organizations controlled, and managed, by disabled people across the UK. Its activities focused on progressing disabled people's inclusion within society and positioning disability as a human and civil rights issue (BCODP, 1997). Publications by the BCODP, which were disseminated as resource packs to support the local mobilization of disabled people, referenced the social model in two specific ways. The first is to highlight the importance of self-representation and ensure disabled people remained key actors in the design, development, and delivery of policies and initiatives associated with disabled people's life chances. And the second is to emphasize the extensive range of barriers that emerge through social world organization. It was intended that disabled people, locally, would establish resistance practices in order to challenge injustices experienced by the disabled people's community. According to Campbell and Oliver (1996), BCODP was a turning point in UK disability politics as it promoted a social interpretation of disability, which rejected individualized and tragic narratives associated with disablement. BCODP closed in 2017; however, since the 1960s, social model significance has continued across the UK.

DPOs are essential for campaigning on inclusion and participation agendas, delivering community-based services, and engaging in policy-making processes (Young et al., 2016). Often, the social model serves to commit organizations to pursue disabled people's emancipation through engagement of strategies, actors, and processes. Across the UK, DPOs refer to the social model extensively. The Reclaiming Our Futures Alliance, which is a consortium of DPOs engaged in defending disabled people's existing rights, uses the social model as a way to maintain national and international partnerships. Their statement (ROFA, 2016) focuses on the importance of operating within an international Disabled People's Movement, and their work includes producing aspirational visions for an inclusive society, contributing to UNCRPD Shadow Reports and instigating direct action campaigns. Here, the social model is employed for different outcomes. It is used to articulate an alternative vision for organizing society, one that promotes inclusion and accessibility. This is of strategic importance to organizations because it assists with building solidarity across the membership. Individuals work together, united in presenting an alternative to the current arrangements that constitute society. The model also serves as a tool to critique and analyze the current practices and ideas that perpetuate disabled people's marginalization. It assists with the identification of problems and barriers that restrict disabled people's participation in society.

Another organization, Sisters of Frida, operates as a collective for disabled women to share experiences, provide mutual support, and articulate the injustices experienced by those at the intersection of gender and disability. Following the coronavirus pandemic, the collective have produced guidelines on accessible online communication (Sisters of Frida, 2021). The guidelines provided information on disabled people's rights to accessible information and suggested action plans for improving disabled people's access to existing online platforms. The guidelines reference the social model as a suitable framework for presenting the accessible features necessary for improving disabled people's participation. Here, the social model is used to guide individuals toward the removal of barriers and the development of inclusive-based solutions.

In the context of mental health, Beresford et al. (2016) have proposed supporting individuals with mental health conditions and experiences of mental health services to embrace the social model. Their empirical study identified that people using mental health services would often have their experiences interpreted through an individual model approach (Oliver, 1990). This would lead to individuals internalizing their experiences of injustice and marginalization and relying on medical treatments and rehabilitative interventions to navigate disabling barriers. Participants felt it was difficult for survivors of mental health services to engage in existing disability politics. Tensions emerged between existing demands and ideas promoted through broader disabled people's social movements and the key issues affecting people with mental health conditions. Nevertheless, survivor networks and advocacy groups on mental health have highlighted the need to incorporate social model principles within the design and delivery of mental health support provision (Beresford et al., 2010). The social model has also been applied to neurodiversity activism. Graby (2015) argues for coalitions between neurodiversity social movements and disabled people's social movements. It is suggested that solidarity can be established by demanding an acceptance of human variation and rejection of the normalizing of human bodies. This would align mad activism, neurodiversity activism, and disability politics to challenge the normative tendencies associated with impairment and biology and focus on promoting inclusion and accessibility.

It is evident that the social model remains significant to the collective mobilization of DPOs in the UK and beyond. Nevertheless, the model is important at the microlevel and in supporting individuals through their personal navigation of disablement. Crow (2007) discusses how the model has facilitated disabled people's exploration of self-worth and the building of a collective, political identity. It has supported individuals to resist internalized oppression and challenge the narratives, values, and practices that undermine disabled people's position in society. For Morris (1991), the model is essential for challenging personal tragedy narratives; however, it should not come at the expense of denying individuals an exploration of the personal experiences of disability. This raises an important point about the social model and personal experience. Activists and academics have suggested that the social model denies the significance of impairment effects (Shakespeare & Watson, 2010), and historical DPOs – such as the Liberation Network – have called for disability activism to acknowledge the impact of impairment upon individual functioning and emotional well-being (Liberation Network, 1981). A route through this is to ensure disabled people, and their organizations, determine how the body and impairment are framed within public discourse, policy development, and political action. Returning to Morris (2013), activist spaces should allow for the discussion of the body and impairment, but, crucially, this should be contextualized within a call for access requirements, sufficient support, and a rejection that impairment equates to personal inadequacy.

According to French and Swain (2008), concerns have been leveled at the social model with regard to its inclusion criteria. Historically, its initial development was led primarily by those with physical impairments. This resulted in claims that the model is applicable only to individuals with physical impairments. While there are justifiable claims that there exists a hierarchy of impairment within disability politics and activist mobilization (Deal, 2003; Reeve, 2014), academia and activist networks have worked to demonstrate the model's relevance to all disabled people. Finkelstein (1987) proposed a narrative for disability culture through using the social model to build a collective identity. Individuals, in the exploration of the social model, would become aware that all disabled people experience forms of isolation, segregation, and oppression. Common experiences are identified through similar patterns of injustice, which emerge through the conditions and arrangements located within society. Nevertheless, it is important to recognize that such experiences would differ and individuals would have various diagnosis, conditions, and impairment effects. The importance of disability culture would encourage disabled people to pursue collaborations and forms of solidarity to challenge conditions that perpetuate their marginalization (Lawson, 2001).

The chapter will now consider future mobilizations of disability activism and the implications, and opportunities, which arise through social model application.

The Future of the Social Model

The social model has endured a misconception that has resulted in an irresolvable debate over its validity and usefulness. Discussions on the social model have often presented it as a theory (Bunbury, 2019; Shakespeare & Watson, 2001). This has complicated the application of the social model, as commentators seek to argue whether or not it provides an all-encompassing, grand theory to explain disability. It is important to clarify that those engaged in developing UPIAS' interpretation of disability, which is referred to as the social model in this chapter, did not present or discuss it in terms of theory. Finkelstein (2001) argues that the social model does not explain disability, nor does it position disabled people as the subject matter within the social interpretation of disability. A key point is to determine what the social model does. To answer this, Beckett and Campbell (2015) introduce Hawes' (1975) distinction between theory and model. Whereas a theory provides an explanation, a model offers a description of the properties, functions, features, and characteristics of an object or process. This is important for the sustainability, coherency, and prominence of disability activism. The social model serves to describe the experience of disablement, which activists can use to produce influential strategies and activities for social change. A theory can become entangled within the social model, to offer an explanation as to why disability occurs and is reproduced through the arrangements within society. For example, some UK activists (Clifford, 2020; Williams-Findlay, 2020) combine the social model with specific economic and political theories to determine how, and why, capitalism produces disablement.

Moving forward the social model must remain open and accessible to activists. Its significance comes from disabled activist networks using it flexibly, as part of an array of strategies to realize disabled people's emancipation. According to Oliver (2013) the model is a tool, which can be applied to improve people's life chances and conditions. Rather than debate its validity, activists and disabled people's social movements should use it to build solidarity and progress agendas relevant to the activists involved. It continues to hold relevance within the arenas pertinent to disabled people's participation and inclusion within society, such as research design (Stone & Priestley, 1996), policy and legislative development (Lawson & Beckett, 2020), training and knowledge transfer (Walker, 2004), and radical activist mobilization (Hunt, 2019).

Beckett and Campbell (2015) have sought to position the social model as a form of resistance, a way to present contemporary experiences of disablement and produce radical or reformist alternatives to organizing the social world. Here, the social model is understood as an oppositional device (Holmes, 2007) rather than a tool. It introduces necessary and important questions for disability activism: what current arrangements and practices need to be resisted, what are the alternatives, and what is required to enact or sustain resistance? Framing disability activism and politics through a lens of resistance would assist with shifting the focus away from the endless, and unnecessarily complicated, debates over its validity. Through enacting resistance, possible and preferable futures can be presented and explored by activists. The significance of the social model, as a strategic device for progressing disability politics, remains ever-present. Combining the social model with resistance guides activists and social movements to consider the conditions that create an unjust society in the present, as well as the conditions required to produce and sustain an inclusive and accessible future. For Beckett and Campbell (2015), this means the model can facilitate understanding of how people with impairments exist in society and create dialogue and action to resist the widespread oppression.

The key to the longevity and sustainability of disability activism is ensuring newcomers and less established members have opportunities to learn, influence, and contribute to strategies and agendas. Disabled people's social movements need to maintain open, and accessible, spaces for groups to discuss the principles and application of key concepts underpinning disability activism. Empirical research by Griffiths (2019) identified challenges faced by young disabled people when engaging in the UK Disabled People's Movement. Young disabled people continue to face restrictions on debating social model application within disability politics. They want opportunities to consider the contemporary relevance of the social model in their daily lives and determine how it can support activities to realize an inclusive society. Young disabled activists expect to influence established strategies rather than occupy positions of passivity and dependency. Their intentions are to provide counter-rationalities, which disrupt the existing arrangements that reinforce disabled people's marginalization, but this is often denied by established members and DPOs.

Intersectionality remains an important issue within disability activism (Erevelles, 2011). Disabled people should be supported to explore the daily experiences that emerge through the intersections of their identities. This will broaden disability activism membership and incorporate diverse perspectives and voices into activist strategies. Further research and activist accounts are required to understand the significance of intersectionality in disability politics. The social model may assist disabled activists to engage in social justice issues within, and beyond, disability. Its emphasis on understanding the arrangements within society that are imposed, unnecessarily, on marginalized communities can support broader coalitions of social movements to counter injustice.

Conclusion

This chapter argues that the social model has an important history in the development and organization of disability activism, disability politics, and disabled people's social movements. It was – and remains – instrumental in politicizing the experiences of disability and highlights the political, economic, cultural, and social arrangements that deny disabled people opportunities to participate in their communities. The social model is likened to the concept of the Sociological Imagination (Wright-Mills, 1959), insofar that it provides an awareness of how the personal experience of disability can be understood through the processes, relations, and contexts that produce the social world. By placing emphasis on how society establishes and reproduces marginalization and oppression, disabled people develop an understanding that their biography, experiences, and life chances are affected by societal organization.

The significance of the social model can be identified in three ways. Firstly, the model supports individuals in their journey toward liberation and empowerment (Crow, 2007). It assists individuals to navigate away from dominant narratives of tragedy and body-mind normality and can challenge assumptions that individuals with impairments and health conditions should accept responsibility for the barriers they experience. Secondly, the model is equipped as a tool by activist networks and social movement organizations to instigate radical emancipatory politics (Lawson & Beckett, 2020). It supports disabled people's collectives in developing resistance-based practices against the arrangements, actors, and networks that sustain disabled people's marginalization. The model facilitates discourse and praxis aimed at furthering disabled people's social justice and establishing accessible and inclusive societies. Thirdly, the model remains instrumental within organizational policy and is employed often as a framework to teach professionals about disability equality and social justice (Bunbury, 2019). The adoption of the social model within policy design and delivery transcends the divide between public, private, and civil society sectors – it remains a reference point for government strategy, service delivery, professional development, and inclusion of disabled people's organizations within training and knowledge delivery.

The chapter further argues that there is a danger surrounding social model application in disability activist networks. Notwithstanding its essential role in progressing disability politics, its application has allegedly been employed dogmatically (Shakespeare & Watson, 2001). The UK Disabled People's Movement continues to be scrutinized over how existing activists and newcomers are discouraged from critiquing the model's value (Griffiths, 2019). Disabled people's organizations and networks need to give consideration to developing safe and accessible spaces, which will explore the model's contemporary relevance in the lives of disabled people across the life course. This will support newcomers to disability politics to understand and utilize the social model in their daily lives, as well as facilitate their ideas about how the social model is employed to realize disabled people's emancipation.

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Disabled People's Mobilization Around a Human Rights Approach to Enhance Their Participation in Law and Policy Making in Iceland

14

Laufey E. Löve and Rannveig Traustadóttir

Contents

Abstract

The right to have a say in decisions that affect one's life is a core human right and a key emphasis of the Convention on the Rights of Persons with Disabilities (CRPD). Securing this right serves to empower disabled people and establish their position as "experts" in matters that affect their lives. This chapter examines how the CRPD and the human rights approach to disability that it embodies have served as a catalyst for the adoption of a new approach by disabled people's organizations (DPOs) to putting pressure on the authorities to engage in a more robust way with DPOs in the development of laws and policies, as called for by the Convention. It draws on the example of the process leading up to the adoption of new core disability service legislation in Iceland, which saw the emergence of the DPOs' use of the CRPD, as well as the General Comments by the CRPD Committee, as a tool to effectively advance the rights of persons with disabilities. This new strategy resulted in key changes to the legislation at the last stages of consultation.

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Convention on the rights of persons with disabilities (CRPD) · Disabled people's organizations (DPOs) · Human rights approach · Social understanding of disability · Disability activism and advocacy · Policy making

Introduction

The adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD) (2018a, b) not only propelled disability rights onto the international agenda, but it also had a significant impact within academia, particularly in the field of disability law and disability studies, where it led to the development of a new theoretical approach, the human rights approach to disability. As Quinn and O'Mahony (2017) point out, this approach is both driven and supported by the Convention itself. The CRPD and the human rights approach to disability reject the prevailing and often unquestioned perception of disabled people as a social or a medical problem in need of fixing or repair and instead recognize disabled people as rights holders who are more often disabled by barriers created by society than their impairments (Kanter, 2015; Traustadóttir, 2009). The perceived problem is therefore located outside the disabled persons, requiring changes to society to accommodate the difference brought about by disability (Degener, 2016; Kanter, 2007). The human rights approach thus merges the social approach to disability, which regards disability as the result of barriers created by society, with recognition of disability as a human rights issue (Degener, 2016; Kanter, 2007; Quinn & O'Mahony, 2017). From this perspective, the focus turns to society's role in constructing disability and its responsibility to rectify disability-based exclusion (Stein & Stein, 2007). Limitations that are placed on disabled people are identified as violations of their human rights, and the point of reference is changed by substituting needs with rights that can be claimed (Kanter, 2015). As rights holders, disabled people are, therefore, entitled to provisions being made to ensure their ability to exercise their rights (Degener, 2016; Kanter, 2015; Office of the High Commissioner for Human Rights, 2010; Stein & Stein, 2007). At the core of this approach is the Convention's embrace of the substantive equality model, which does not simply call for the equal treatment of all, but rather that people be treated in such a way that the outcome for all is equal (Kanter, 2015). By taking this stand, the Convention recognizes the need to adjust or adapt the traditional principle of equality, "not as an exception, but as a logical requirement to effectuate the true substance of the principle of equality and non-discrimination itself" (Arnardóttir, 2009, p. 60). Recognizing substantive equality establishes a positive obligation by state parties to remove barriers to full equality where relevant (Arnardóttir, 2009; Kanter, 2015). The Convention also develops a new understanding of equality as inclusive of difference, relating to both personal and group differences, as well as differences stemming from socioeconomic disadvantages (CRPD Committee, General Comment No. 6, 2018a).

The Convention and the human rights approach radically shift the focus to what changes need to be made and by whom. What is more, they go further than just stipulating rights and responsibilities. One of their most important contributions is that they lay out a roadmap to achieving change (Degener, 2016). The articles of the Convention themselves serve as a forward-looking guide illuminating the changes needed, with further support provided by the General Comments of the CRPD Committee on the interpretation and implementation of key rights. As such, the human rights approach and the Convention are tools that serve to empower disabled people to claim their rights as human rights holders (Degener, 2016; Skarstad & Stein, 2018).

This chapter focuses on the Convention and the human rights approach to disability as tools to further disability rights. It will do so from the perspective of the Convention's emphasis on the right of disabled people to full and effective participation in the development of laws and policies that affect their lives. The chapter draws on the case of Icelandic DPOs, which strategically used the Convention and the human rights approach to disability as tools to press for changes to core Icelandic disability legislation*, Laws pertaining to services for disabled people with long-term support needs* (No. 38/2018), in the final stages of negotiation before the law was passed by Althingi, the Icelandic Parliament, in 2018. The process, which was a part of the country's ratification of the CRPD, was formally initiated with the establishment in the spring of 2014 of a working group tasked by the Minister of Social and Housing Affairs with drafting the legislation and came to a conclusion in the fall of 2018 when the new legislation became law. The research this chapter draws on examined this process through 18 in-depth interviews, conducted from 2016 to 2018, with leaders of DPOs – both established DPOs, which included umbrella organizations, and grassroots and activist groups. In addition, data were gathered through the analysis of documents that consisted of comments submitted by disability groups and organizations on the draft legislation, as well as written communications between DPOs, academic research institutions, and the authorities during the consultation process (Löve et al., 2018, 2019). The study critically examined to what extent Icelandic authorities have lived up to the obligation to ensure active participation, as stipulated in Article 4.3 of the CRPD, and the strategies developed by DPOs to influence policy. The research showed that in the 5 years that the drafting of the legislation took, there was a change in how DPOs approached the authorities, as they increasingly adopted the human rights approach to disability in the later stages and employed the CRPD as a tool to build unity and strategically enhance rights.

Call for a New Way of Doing Disability Law and Policy

Among the most important changes called for by the CRPD is its commitment to ensuring the right of disabled people to full and effective participation in the development, monitoring, and implementation of disability rights. This is a right that promises to fundamentally change the position of disabled people from having decisions taken on their behalf to being a part of writing the narrative of where society is headed with regard to disability rights. The emphasis on full and effective participation is firmly grounded in the obligation set forth in Article 4.3, where state parties are required, "when developing and implementing policies and legislation concerning persons with disabilities," to "closely consult with and actively involve persons with disabilities" through organizations that represent them (Article 4.3). As Lord and Stein (2010) point out, this emphasis is both implicitly and explicitly woven throughout the text of the Convention, with support in the Convention's preamble, as well as in its mandate that "Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process" (Article 33.3). Together, these obligations reflect the fundamental principle that those most affected have the right to participate in decisions that impact them and represent one of the most progressive marks that the CRPD makes toward the development of human rights law (Stein & Lord, 2010, p. 698). It is a position that opposes the marginalization and lack of voice in decision-making processes that so often has been the lived reality of disabled people and aligns with and reflects the rallying call of the disability movement, "Nothing About Us Without Us."

Indeed, the powerful participatory focus that runs through the CRPD can be attributed in great part to the unprecedented involvement of civil society, particularly DPOs, and the unique drafting process that was adopted as a result. The drafting of the Convention itself established a precedent for a collaborative process and gave the Convention a direction that is one of its enduring legacies, that of ensuring the due influence and participation of disabled people in their own affairs and in setting laws and policies that affect them, as citizens and representatives of people who have the lived experience of disability.

To further emphasize the Convention's intent and to underline the obligation upon state parties to ensure effective participation in the development of laws and policies, the UN CRPD Committee clarifies that this obligation should be broadly interpreted to cover all legislative and administrative measures that impact the rights of disable people either directly or indirectly, including general laws such as the public budget (CRPD Committee, General Comment No. 7, 2018b). Furthermore, the Committee addresses what constitutes inclusive and participatory policy making by providing detailed and thorough guidance on how to ensure full and effective participation and by providing a guide to the process of producing policies and legislation that are truly collaborative and inclusive. It is, moreover, important to note that while Article 4.3 calls for the participation of disabled people through their representative organizations, the Convention's intent is not to distance disabled people from participation in decision-making processes. The Committee provides clarification in this regard by defining what constitutes a DPO, as "those that are led, directed and governed by persons with disabilities. A clear majority of their membership should be recruited among persons with disabilities themselves" (CRPD Committee, General Comment No. 7, 2018b). This clarification is of key importance as it leaves no doubt that the intent of the CRPD is to ensure that disabled people themselves have access to all decision-making processes and that disabled people are recognized as capable and an important source of knowledge with regard to decision-making that affects their lives.

By bringing disable people into the decision-making process as active contributors, the CRPD ushers in fundamental changes to existing process norms with regard to how disability policy is made and who is involved. It calls for a co-production of social policy where the contribution of disabled people and the lived experience of disability are essential, while at the same time adhering to core principles of representative democracy, recognizing that opinions, suggestions, and comments will not automatically translate into law and policy (Löve et al., 2017). What it does is that it obligates state parties to change established process norms in a culture where "persons with disabilities still face significant attitudinal, physical legal, economic, social and communication barriers to participate in public life" as stated in General Comment No. 7 (para 5) (CRPD Committee, General Comment No. 7, 2018b). By taking this stand, the Convention challenges existing and taken-for-granted power relations and calls for changes to the accepted norms of who makes disability policy, rejecting the often ingrained perceptions of disabled people as lacking in decision-making skills (Arstein-Kerslake, 2017). The right to effective participation in law and policy making has the potential to shift the uneven power balances that have resulted in the marginalization of disabled people and serve as a tool that empowers them in the fight for full disability rights. This stance has been identified as pivotal to changing the position of oppression and disempowerment of marginalized groups by those writing from a critical theory perspective, such as Charlton (1998), Keys (2017), Oliver (1990), Priestley et al. (2016), and Young (1990). As Young emphasizes, only by being a part of the political structure, engaged in setting the political agenda and defining and re-defining issues in a way that reflects their lives and needs, will marginalized groups be able to change their position of marginalization (Young, 1990). In essence, the Convention calls for a radical shift of existing process norms that, as Quinn and O'Mahony have pointed out, provide "unprecedented opportunity for persons with disabilities to influence law and policy locally, nationally and globally" (Quinn & O'Mahony, 2017, p. xxv).

The New Approach in Practice

The human rights approach highlights the role of the CRPD as a guide and a tool for advancing disability rights. The process leading up to the adoption of new core disability legislation in Iceland, *Laws regarding services for disabled people with long term service needs* (No. 38/2018), provides an example of how this approach can be used strategically to advance disability rights.

The drafting process commenced in 2014 when the Minister of Social and Housing Affairs established a working group to prepare legislation that would replace core disability service legislation dating from 1982. From the very beginning, there were troubling signs of a lack of emphasis on ensuring the active participation of disabled people and their representative organizations in the process. The working group was comprised of 12 members with only 2 appointed by DPOs, or 17%. The small representation of DPOs was criticized, as was the fact that the DPOs represented did not at the time fully meet the CRPD's criteria for disabled people's organizations, as defined in General Comment No. 7, i.e., that they be led, directed, and run by disabled people themselves and that more than half of their membership consist of disabled people. In addition, during its 3 years of work, the membership of the working group included only one disabled person, and after this person's resignation half way through the drafting process, no disabled person was a part of the group for the remaining 1.5 years, until it concluded its work in October 2016. The lack of acknowledgement of the CRPD's emphasis on the importance of including disabled people themselves as representatives of the lived experience of disability was concerning and strongly criticized by grassroots and activist groups (Löve et al., 2017).

Concern over the lack of sufficient representation and active participation of disabled people and their representative organizations was also reflected in the in-depth interviews with the leaders of DPOs. They talked about an "incredible reluctance" and that their suggestions, petitions, and opinions often went unheard by the authorities and were rarely taken into account in policy making processes. This perception was shared by both the leaders of the established organizations, including the two umbrella organizations that had the right by law to be consulted on policies concerning disabled people, and the representatives of grassroots and activist groups. Expressing frustration that at times it felt as if decisions had already been made before meetings were convened, some even talked about having to be vigilant to ensure that comments and opinions expressed by their representatives were included in the minutes of the meetings (Löve et al., 2018).

Despite these frustrations, the approach of the established DPOs to influence the authorities continued to be marked by a reluctance to assume an aggressive stance or make outright demands. At the forefront was the emphasis on the need to maintain a collaborative and cordial relationship that focused on building trust and the DPOs' credibility as negotiating partners, including "cultivating a reputation for being trustworthy, calm and professional as opposed to emotional or aggressive" (Löve et al., 2018: 4). Maintaining an open dialogue was a cornerstone of their strategy, and their perception of their position vis-à-vis the authorities in the consultation process was reflected in statements such as "we don't burn bridges," "we don't slam doors," and "we are not loud" (Löve et al., 2018: 4). At times, they described their strategy as having to come to terms with taking small steps toward a set goal rather than having to accept no gains at all.

At this stage of the consultation process, the position of the DPOs was marked by their perceived need to maintain their foothold and position as reliable partners, which draws attention to and highlights the unbalanced power relations that existed and how it had put the DPOs in the position of having to monitor the tone of their demands and expectations. However, during the course of the research, a shift was observed in this regard that saw the gradual empowerment of the DPOs, fueled by the CRPD and the human rights approach during the last stages of consultations before the law was adopted into law by Althingi in the fall of 2018.

The position of grassroots and activist groups, which did not have consultation status in the policy making process, differed and was not as restricted by concerns over maintaining a perception of being calm and trustworthy. They often used more visual and visible forms of expression, such as wearing chains around their necks in public to represent systemic hindrances, organizing demonstrations, and delivering petitions to the authorities (Löve et al., 2018). Their demands were often marked by a more outright insistence on greater representation of the lived experience of disability. They pointed out that this emphasis was often missing from the strategies of the established DPOs. In a comment sent to Althingi regarding the policy making process, one grassroots activist group criticized openly the lack of DPOs nominating disabled people; "[i]t is very problematic that more often than not they [the DPOs] send non-disabled people to the table" (Althingi, 2017).

Following the initial drafting stage and review by the Welfare Committee of Althingi, the draft legislation was opened for comments in the spring of 2017, receiving 36 comments, from public, private, and academic institutions, as well as organizations, groups, and local authorities. It drew strong criticism from DPOs and the research community, among other things, for the lack of full and effective consultations as called for by the CRPD (Löve et al., 2017).

The legislative process had lingered and was now in its fourth year. However, pressure to finalize the process had been building following Iceland's ratification of the Convention in the fall of 2016. In addition, changes to the political leadership, including the composition of the Althingi's Welfare Committee, following general elections in the summer of 2017 had led the leaders of DPOs to believe that there was now an increased willingness to engage in an inclusive and co-operative policy making process. Seizing the opportunity, a joint working group was convened, comprised of representatives and leaders of key disabled people's groups and organizations, as well as the research community.

This was a new approach, as, prior to this, the DPOs had primarily worked independently, often focusing on issues particular to their members' interests and needs, which had resulted in diverging areas of focus that could, for example, be observed in the comments submitted by DPOs to the draft legislation. The spectrum of disability organizations (which includes both DPOs and DOs) in Iceland is broad, with two leading umbrella organizations, the National Disability Alliance (NDI) (Öryrkjabandalag Íslands) and the National Association of Intellectual Disabilities (NAID) (Landssamtökin Þroskahjálp). In addition, there are several other established organizations, including the Icelandic Federation of Physically Disabled People (Sjálfsbjörg), the Icelandic Association of the Visually Impaired (BIAVI) (Blindrafélagið), the Icelandic Association of the Deaf (Félag heyrnarlausra), and the Association of Rehabilitated People with Spinal Cord Injuries (Samtök endurhæfðra mænuskaddaðra). There is also a vibrant and growing community of grassroots and activist organizations, including Tabú – Activist feminist disability group, the Organization of People with Intellectual Disabilities (OPID) (Átak), and the Center for User-led Personal Assistance (CUPA) (NPA Miðstöðin), which have been vocal and often been able to generate media attention.

The key factors that contributed to bringing DPOs together were the perceived urgency to push for changes in the final stretch of consultations, changes in the political leadership, and the need to respond to complaints from several politicians that inconsistencies in the comments, proposals, and suggestions by the various DPOs prevented the parliamentarians from incorporating them in the drafting. The strategy adopted by the informal working group was to focus exclusively on issues that all could agree upon and to leave other matters to be pursued by each organization separately. The Convention provided a natural foundation for this collaboration as all the participating groups and organizations emphasized and referred to the Convention, and the rights and core values it embodies, in their agendas and mission statements. The Convention, therefore, served to focus the DPOs on common interests and shared values and, thus, helped to empower them to stand together and present a united front. "It's hard to ignore us when so many of us are there all saying the same thing" (member of the joint working group).

Members of the working group also increasingly approached the authorities from a human rights perspective, emphasizing rights as opposed to asking for consideration of needs and citing articles of the Convention and their interpretation by the CRPD Committee to support their arguments. A sense of empowerment could be observed as a result of this change. One member stated, "[t]here is a lot more power to it when we can claim a right instead of relying on the willingness of others." The increased use of a rights-based approach was also a reflection of the considerable accumulation of knowledge of the Convention and its key articles among the DPO members and the research community. A member of the group recalled an instance when a member had read out loud before a meeting of Althingi's Welfare Committee a passage from General Comment No. 5 in support of his argument regarding interpretation of Article 19 of the Convention.

There was also an increased willingness to frame issues as violations of rights. As a member of the working group pointed out, "[w]hat I say to people is, just to be clear, this is no longer a question of choice because when Iceland ratified the Convention, it accepted its obligation to consult and ensure participation. If it's not done, then you are in breach of it" (member of the joint working group). The previously expressed hesitation to adopting a confrontational stance vis-à-vis the authorities had also dwindled, as exemplified by a member of the joint working group who, after finding out that the drafting of several regulations had been initiated without calling disabled people or their representative organizations to the table, reported meeting with the Minister of Welfare to protest. "I handed him [the Minister] a document to sign stating our protest . . . pointing out that this was in violation of the CRPD. Two weeks later, we were called to the table" (member of the joint working group). Compared to the more guarded approach that DPOs had previously maintained, these changes signaled an important perception of a shift in the balance of power where DPOs, drawing on a rights-based approach and a united front, felt empowered to represent their case and their claims to full disability equality more forcefully than they had before.

The new unified rights-based approach resulted in several significant changes to the legislation that members of the working group attributed to their efforts during the last round of consultations in early 2018. These changes included an addition to Article 36 of the law that now states that the membership of a consultative body to the Minister is to be composed of a majority of disabled people. This was considered to be a major breakthrough. A member of the joint working group stated, "[i]f the consultative committee is led by disabled people, then I'm confident we can do what we set out to do." In addition, there is now an increased emphasis on the need to consult with DPOs throughout the text of the legislation, whereas before there had only been references to consultations with local governments. Another major achievement that the group attributed to its work was the fact that the law was changed to secure personal assistance as a legally mandated service form for all disabled people. Before, the draft had contained contingencies that could be used to limit the access of children and people with intellectual disabilities.

The working group also succeeded in changing the name of the legislation. It now refers to services for disabled people with "long-term" service needs instead of "significant" service needs as it did before. The change was intended to avoid "leaving it too much in the hands of the local governments to determine how much support you need and therefore whether the law applies to you or not. . .." Members pointed out that there could be financial interests at stake that could impact decision-making. In addition, members of the working group, drawing on their expert knowledge of the CRPD and its fundamental intentions and goals, were influential in the translation of key definitions, ensuring that they were in line with the intent of the CRPD (Löve et al., 2019).

What Changed and Why?

The study revealed a change in the way that the Icelandic DPOs approached the authorities in the 5-year drafting process. The change that occurred can in significant part be explained by the DPOs' embrace of the human rights approach to disability, focusing on rights instead of being dependent on politicians' willingness to accommodate needs, and their strategic use of the CRPD as a tool to build unity and to push for rights. The social understanding of disability, as a foundation principle of the CRPD, was also of great significance, stating that disability is the result of the interactions of people with impairments "with various barriers [that] may hinder their full and effective participation in society on an equal basis with others" (Article 1). This clearly supported the DPOs' demands regarding the importance of societal changes.

The use of the CRPD as a tool by the Icelandic DPOs was multi-pronged. Firstly, the DPOs drew on the Convention's ability to act as a unifying force by bringing together key DPOs and grassroots organizations, with the support of the research community, to create a united front. Previously, the DPOs had primarily engaged with the authorities separately, often focusing on areas of particular relevance to their membership. As is the case in other countries, the diversity of the Icelandic DPOs is a reflection of the diverse nature of disability itself and has served to facilitate the growth of the Icelandic disability movement to better reflect the breath of issues relevant to disabled people (Encalada, 2020; Sherlaw & Hudebine, 2015). In this instance, however, the Convention was uniquely able to support the DPOs in coming together around its core values and the rights that they all shared and had advocated for in their agendas and mission statements. The CRPD, therefore, served as a tool to unite and empower the DPOs who reported finding themselves better positioned to argue their case as representatives of a broad coalition that included a wide spectrum of DPOs with diverse memberships. The group also reported that working together had served to empower and strengthen their position as it had enabled them to share the workload and draw on the various strengths and expert knowledge that each organization and group brought to bear.

Secondly, by adopting a human rights focus, members of the working group strategically employed the Convention as a tool by citing and referring to rights stated by the Convention and underlining the obligation on state parties to ensure that these rights are realized. Furthermore, they drew on their in-depth knowledge of the Convention's intentions and values to support their arguments, for instance, by citing the interpretations of key articles by the CRPD Committee, articulated, among other places, in the Committee's General Comments. Members of the working group also drew on the potential underlying political threat to the authorities of being found to be in violation of disabled people's human rights. This was exemplified by the working group member who requested that the Minister of Welfare sign a document stating that he had been made aware that his actions were in violation of the obligation to ensure active participation of disabled people in policy making, as called for by Article 4.3.

Thirdly, Article 4.3 of the Convention is in itself a tool for advancing disability equality that the DPOs strategically seized upon in their efforts to influence the authorities and, as such, helps explain the shift that occurred in the balance of power between the Icelandic DPOs and the authorities. As stated earlier, the right called for in Article 4.3 represents a fundamental change to existing process norms with regard to how disability policy is produced and who is involved in that process. By obligating the authorities to ensure full and effective participation of disabled people, the Convention calls for a fundamental shift from previously taken-for-granted power balances. In the case of the Icelandic DPOs, this was highlighted by the shift in attitude among the DPOs, from viewing it as their role to be accommodating and, in effect, practicing self-monitoring in order to maintain an open dialogue to demanding an inclusive and effective dialogue as a right. The shift observed reflects the critical theory's focus on questioning and re-examining assumptions and values previously taken for granted. Instead of accepting the status quo, critical theory recognizes that existing social norms and structures are an expression of a particular power structure (Agger, 1989; Minow, 1990). Critical theory claims that only by revealing the underlying power dynamics that maintain the status quo can change take place (Kellner, 1993; Meekosha & Shuttleworth, 2009). Article 4.3 calls for such a reevaluation of existing power structures and obligates states to take a step toward creating a new power balance by securing the full and effective participation of disabled people through their representative organizations in the development of law and policies.

The intent of Article 4.3 is to empower disabled people as full and effective partners in the co-production of disability policy. The right that it encapsulates has the potential to shift the uneven power balances that have resulted in the marginalization of disabled people and to serve as a tool for the empowerment of disabled people in the fight for full disability rights. Article 4.3. exemplifies how the Convention and the human rights approach may be employed as tools to empower disabled people to claim their rights as human rights holders (Degener, 2016; Encalada, 2020; Skarstad & Stein, 2018).

Conclusion

The process of influencing the key disability legislation in Iceland represents a successful example driven by a coalition of the disability rights movement. As has been documented by other activists and advocates around the world (Soldatic & Johnson, 2020), it is primarily the CRPD that has created the international momentum for change, which the Icelandic disability movement has translated into action. The CRPD empowers disabled people by providing new ways to advocate for their rights as well as open new avenues to interact with governments. The embrace of the human rights approach to disability by the Icelandic DPOs, and their use of the CRPD as a tool for asserting pressure in the advancement of their rights, including the right to full and effective participation in law and policy making, served to empower disabled people and the DPOs in their dealings with authorities. Furthermore, it resulted in a change in the balance of power that had previously been taken for granted, including by the DPOs themselves.

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Models of Disability and Judicial Interpretation in India

15

Sanjay Jain

Contents

Abstract

How disability is modeled or understood is determinative in the evolution of both Disability Studies and Disability Politics. By focusing on India, this chapter demonstrates that transformation and metamorphosis in the lives of persons with disabilities is contingent and predicated on the adoption of models to evolve conceptions of disability and disability rights. Upon the ratification of the United Nations Convention on the Rights of Persons with Disabilities 2006 by India, a presumption arose that the Indian legal order embraced the social and Human rights models of disability and that disability was no longer to be viewed through the prism of the Medical Model. The judiciary is enjoined to be cognizant to and sensitive of these presumptions while interpreting the Constitution and other

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laws, just as the legislature and executive are mandated to reflect the same in the enactment and execution of laws.

This chapter investigates how the judiciary has drawn upon the social and human rights models of disability in advancing the rights of persons with disabilities. The challenges faced by the judiciary in carrying out this role are also addressed. As Dhanda has argued, the approach of courts in India to disability rights cases continues to be dominated by a narrow focus on the facts of each particular case rather than an ambition for more systemic change (Dhanda, 2005). Nevertheless, there are some interesting and potentially important exceptions, which draw upon the social and human rights models of disability implicitly or explicitly.

Keywords

Models of Disability · Supreme Court of India · High Courts · Constitutions of India · RPwD Act 2016 · PWD Act 1995 · UNCRPD

Introduction

This chapter seeks to interrogate how the judiciary has deployed the social model and the human rights model of disability. It also demonstrates that courts have strengthened legal obligations based on both these models by recognizing the significance of the obligation to provide reasonable accommodation and the idea of the promotion of accessibility. It suggests that ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) by India played an important role in the deployment of these models by the courts. One of the major steps India has taken post ratification of UNCRPD (to incorporate its obligations as part of the Indian legal order) is to enact the Rights of Persons with Disabilities Act, 2016 (hereinafter RPWD Act 2016). This has had a significant impact on case law, but should not diminish the importance of the judiciary's role in bringing about transformative change – a point elaborated in section "Socio-human Rights Model of Disability in Judicial Discourse Post RPWD Act 2016." When viewed against the text of the Constitution of India, which is marked by ableism and the medical model of disability, the judicial interpretation of disability – both pre and post ratification of the UNCRPD – includes examples which are remarkably positive.

This chapter is divided into three sections. Section "Models of Disability – An Overview" briefly examines the principal models of disability; section "Disability-Rights Based Adjudication in the Pre-RPWD Act Era" presents an analysis of judgments in disability-related cases which do not explicitly refer to the socio-human rights model of Disability, most of which were decided prior to the enactment of the RPWD Act 2016. It is suggested that, despite the grip of Constitutional silence on Disability-based discrimination, the Courts in India were able to deliver some judgments with powerful potential for change in the lives of people with disabilities during this era. In the third and final section, some of the landmark judgments pronounced by the Supreme Court and High Courts of India, which do explicitly draw on the socio-human rights model, are examined. This analysis focuses mostly on cases decided after the enactment of the RPWD Act 2016 and highlights the catalytic role of the socio-human rights model in the recognition and promotion of the human rights of persons with disability. The division of cases between sections "Disability-Rights Based Adjudication in the Pre-RPWD Act Era" and "Socio-human Rights Model of Disability in Judicial Discourse Post RPWD Act 2016" does not necessarily reflect a major qualitative difference in the approach of the courts, but nevertheless it helps to provide structure to the discussion and lays down useful groundwork for future research. It is argued that Courts have been able to effect some structural changes in the political establishment to embed and entrench the rights of disabled people in the legal order. Some clarifications are in order. I deploy the terminology of "Persons with disabilities" and "disabled persons" synonymously and do not wish to engage in debate on the same in this chapter. Secondly, though the social and human rights models are distinct, for the purposes of this chapter, I read them as an integrated whole and demonstrate during the course of discussion in this chapter that Courts in India have not interpreted them as embodying distinctively different standards. Lastly, I have relied on the judgments of Appellate Courts alone because in India, lower courts are mostly arbiters of facts and, moreover, the judgments delivered by these courts are not reported.

Models of Disability – An Overview

A careful analysis of pronouncements on Disability demonstrates that the judiciary in India has deployed Medical, Social, and Human Rights Models of disability. In this section, a brief account of these models is provided.

Smith correctly points out that, on the surface, the medical and social models of disability appear to be two poles that are mutually exclusive, providing opposing interpretations of the concept of disability, but in reality, these models are part of a spectrum that allows "for a range of interpretations between them" (Smith, 2011, p. 107).

Medical Model

Smith envisages two variants of the Medical Model. According to the first variant, disability is caused by fixed medical characteristics that inevitably result in a life of deficiency and "abnormality" – the full-essentialist individual deficiency interpretation. Although the second variant also locates the cause of disability in medical characteristics, it nevertheless recognizes that such conditions can be "partially alleviated by changes in the social environment, so as to enable some degree of 'normal living'" – the part-essentialist individual deficiency interpretation (Smith, 2009, p. 22).

The full-essentialist individual deficiency approach is opposed by the disability rights movement because the policies and practices based on it render disabled people as passive and powerless targets of intervention through non-disabled expertise. Medicalization of Disability is directly linked to a “practice of genetic eradication and even the systematic murder of people with impairments” (Smith, 2009, p. 16).

Although the second variant seems to embody a move away from this full-essentialist individual deficiency interpretation, because of its recognition of the role of social environments as a cause of disability, reliance on medicalized understanding of disability is still the pivot of this model (Smith, 2011). By perceiving persons with disabilities as problematic, owing to their inability to internalize dominant standards of “normality,” it perpetuates the Ideal or Best. By highlighting the role of non-disabled experts in “changing the individual’s deficient or tragic condition through medical intervention, and/or providing rehabilitation programmes for making individual adjustments to that condition” (Smith, 2011, p 111), the power dynamic in the decision-making process is distorted by being pushed towards the “privileged and expert knowledge” of these professionals.

Thus, under both these variants, there is hardly any focus on the removal of environmental barriers (Morris, 1991; Smith, 2011).

Social Model

Essentially, the social model locates Disability not in an individual’s limitations but in societal failure to provide appropriate services and accessible environments (Hendren, 2020, p. 14).

Firstly, the social model distinguishes between impairment and disability – the former is individual and private, the latter is structural and public. The Social Model calls for a focus on the removal of disability and thus for a shift away from an exclusive focus on the remedying of impairment. Secondly, the social model views disability as a societal construct, whereas the medical or individual models see it as a physical or mental deficiency. Thirdly, distinguishing disabled from non-disabled people, the social model attributes the causes of oppression of the former to the latter. Civil rights rather than charity are regarded as the way out for the empowerment of persons with disabilities. “Nothing about us without us” is the mantra underlying this model (Davis, 2021).

A number of scholars have questioned the efficacy of the social model by arguing, inter alia, that it neither helps in comprehending the complex interplay of individual and environmental factors in the lives of disabled people nor does it account for the number of resources to be allocated for the removal of barriers (Shakespeare, 2021). However, there are also a large number of scholars robustly defending its continued relevance. They contend that this model is relevant internationally in the Disability Rights Movement because of its emphasis on recognition of the distinction between notions of impairment and disability. Even though the goal of this model is to bring societal change, that change will not be successful unless it takes into account various impairment types, effects, and needs. Understood in this way, Degener’s observation that the human rights model acknowledges impairment-effects and demands them to be considered when social justice theories are developed applies equally to the social model (Lawson & Beckett, 2020).

From this discussion, it becomes clear that the social model is neither a dogma nor a theory; it merely is a symbolic representation and articulation of different disabling barriers. Viewed in this light, it is historically, socially, and topographically contingent. For example, in India, apart from placing emphasis on the socio-cultural and economic-politico and legal barriers, it is also important to attend to religious and cultural constructions of disability. In other words, the Indian social model of disability must also combat the notion that persons with disabilities (PWDs) are victims of their past karmas (deeds of previous birth).

The traditional British interpretation of the Social Model, construed as the "politics of disablement" discussed above is only one of the possible theoretical description of causes of disability and does not prevent its further substantive interpretation in order to be attentive to specific policies or practices. Smith offers an alternate interpretation alongside exposing limitations of the British social model. He contends that despite being fundamentally transformative and substantially problematizing both versions of the medical Model, the British version of the social model nevertheless falls back on the mythical binary of "ordinary" or "normal living" and "ideal" and "non-ideal" states of being (Smith, 2011).

Although "deficit" is described as a "social concern," the British Social Model has a flaw in that it focuses on achieving the ideal state of ordinary citizenship. In other words, PWDs are expected to be in a similar condition to non-disabled people. The distinction drawn under Disability constitutionalism in India, between "sound Mind and unsound Mind," also reflects these mythological dichotomies. The recently rolled out draft policy on persons with disabilities is also symptomatic of this. Let me allude to the observations in the policy in the context of employment of persons with disabilities.

> There are also instances where PwDs often shy away from applying for certain jobs fearing social stigma. There is also perception among PwDs that they may be treated differently post entry into organisation. In the absence of an effective integration process, a conducive environment in an organisation for inculcating inclusive culture will be unrealistic.
>
> Some of the constraints PwDs face in the employment market are lower literacy level, lack of daily living skills, lack of self-esteem and confidence, overprotective parents, lack of basic trade skills, poor knowledge of language, health issues, rural disconnect from the market and preference for government jobs. (Draft National Policy for Persons with Disability 2022, p. 40, para 7.6 and para 7.7)

The mythological dichotomies and conformance to Idealist structure are issues that Smith tries to overcome in his alternative interpretation of the Social Model. He opines that inaccessible and discriminatory social contexts, as well as their "social construction," or "social construction of disability" are the main causes of disability. Therefore, it is important to characterize the individual deficit or dysfunction (as well as their opposites – "talent" and "capacity") by relating them to certain social and political processes. This interpretation complements the British social model of Disability by shedding light on "social and political discourses defining what are in the first-place talents and handicaps." It amplifies the Positive aspects of a disabled person's identity, reflecting their subjective experiences of impairments (Smith, 2011).

Human Rights Model

With the entry into force of the UNCRPD, some scholars have advanced the human rights model of disability as a historical progression from the social model. Degener attempts to distinguish the human rights model from the social model through the following propositions:

> Firstly, the social model merely articulates disability whereas the human rights model directs attention to recognition of values as part of disability policy to acknowledge the human dignity of PWDs. Secondly, the ambit of the social model is narrower than that of the human rights model. The former is anchored mainly in anti-discrimination policy and civil rights reforms, whereas the latter implicates first (civil and political) and second generation (economic, social and cultural rights) of human rights. Thirdly, the human rights model is, sensitive to the impact of impairment and its effects on PWDs, by contrast with the subdued response of the social model to the same. Fourthly, the social model does not attach attention to identity politics as a significant element of disability discourse, whereas the human rights model is sensitive to the minority and cultural identities of disabled people. Fifthly, the social model completely rules out disability prevention policy, whereas the human rights model affords a basis and justification for the recognition of the positive dimensions of the same and links it with human rights protection claims. Sixthly, while the social model provides a cohesive narrative as to how two thirds of the billion disabled persons in this world live in relative poverty, the human rights model provides a roadmap for transformation in their lives. (Degener, 2014, pp. 34–47)

Degener is categorical in maintaining that the human rights model is not a substitute for the social model. Rather, she claims, the former develops, builds on, improves, and moves beyond the latter. She agrees with the analysis of Rosemary Kayess and Phillip French that the version of the social model that influenced the drafting of the CRPD was a populist conceptualization of the social model, rather than a critical theory of disability (Kayess and French, 2008). The formulation of the disability human rights paradigm evolved by Stein & Stein has striking resemblances to that evolved by Degener. "Disabled persons are entitled to equality by virtue of their equal humanity, not because they satisfy sameness norms and 'antidiscrimination as well as equality measures' demanding the investment of resources are recognised" (Stein & Stein, 2007, p. 1212).

Similarly, a recent research project led by Maria Berghs directs attention to evolving a new model, the social model of human rights, to contest and combat "the negative disability-related impact on equality, social protection and other human rights of policies such as austerity and the shrinking of welfare states" (Berghs et al., 2019).

However, in a recent paper, the views of Degener have been contested inter alia by arguing that both social and human rights models are complementary and that it is not therefore helpful to regard the human rights model as an improvement of the social model. By advancing what is termed the "complementarity thesis," Lawson and Beckett argue that both models build on and support each other (Lawson & Beckett, 2020). Oliver strikes a cautionary note against multiplying models of disability, given the risk of adding to confusion (Oliver, 2004). It is asserted that the primary roles of the social model are descriptive and heuristic in articulating the causes of disability, while the role of the human rights model is prescriptive in providing guidelines for policies, laws, and programs to foster the identity of PWDs through the principles of human dignity and substantive equality. The evolution of new models, by collapsing descriptive and prescriptive theories of Disability, apart from leading to incoherence analytically, has the potential to cause great dis-service to the Disability Rights Movement.

Thus, it is not the social model but explanatory theories of disablement which account for how disabling barriers exist and persist as noted by Thomas (Thomas, 2004). In the light of the aforementioned discussion, the virtue of the social model to adapt to specific local contexts, needs and circumstances need not be reemphasized (Oliver, 2004). Lawson and Beckett observe that the "…human rights model operates to support the development of particular types of law and policy, together with particular governmental and intergovernmental structures and mechanisms for overseeing and monitoring their implementation. By contrast, the social model is more open textured. It operates in connection with emancipatory disability politics more generally" (Lawson & Beckett, 2020, p. 370).

It is important to highlight the nuances in the debate around these models in order to enable the judiciary to evolve jurisprudence based on relevant conceptions of disability. It also ensures that the judiciary takes into account the efficacy of both the social and human rights model as complementary. Against this backdrop, this paper seeks to evaluate how the Indian Judiciary has deployed these models as a changemaker in the lives of PWDs.

Disability-Rights Based Adjudication in the Pre-RPWD Act Era

In this section, a brief critique of ablism in the Indian legal order, with special reference to the Constitution, is followed by an analysis of the judiciary's responses to disability rights cases prior to the enactment of the RPWD Act 2016. As will be demonstrated, in the majority of these decisions, the courts focused on providing remedies to individuals without a broader structural approach. Prior to all this, the section provides a snapshot of the judicial process.

Broadly speaking, the journey of the judicial process around the world has evolved from the mere application and enforcement of law to its creative and innovative interpretation. This interpretative role of the judiciary has been highlighted and promoted by Dworkin, for whom the concept of law is actuated by the considerations and purposes it seeks to achieve. In other words, he focuses on the purposive role of law by emphasizing its best moral interpretation (Dworkin, 1996). This is a paradigm shift from the conventional approach, which confines the role of judges to merely ironing out minor problems and gaps in the law (Cardozo, 1921).

Dhanda aptly captures the role of the judiciary in the context of disability rights adjudication by pointing out that judges have to make a choice between evolving disability rights jurisprudence or reinforcing the status quo and thereby perpetuating the social construction of disability. These choices are at least partly determined by the language of the statutes and the legislative preferences thereof. However, these choices are also driven by historical ideas of disability based on generosity and charity.

The Indian Constitution significantly restricts the legal framework and offers less room for interpretive judicial maneuvers, because of its medical leanings toward disability. It also stifles the agency of PWDs (Dhanda, 2005). The Indian Constitution fails to explicitly list physical or mental Disability as one of the prohibited grounds of discrimination. Additionally, it prohibits people with disabilities from holding certain forms of public office, such as being a judge of the Supreme Court or High Courts, or a Member of Parliament or the State legislature.

On other provisions of the Indian Constitution too, the influence of ableism is telling. Article 41 one of the Directive Principles of State Policy (not enforceable in the Courts of law) enshrined in Part IV of the Indian Constitution reads, “The State shall, within the limits of its economic capacity and development, make effective provision for securing the right to work, to education and to public assistance in cases of unemployment, old age, sickness and disablement, and in other cases of undeserved want.”

Deploying a very disparaging tenor and tonality, disablement is situated alongside the negative conditions of unemployment, old age, and sickness in this provision. Although the State is obligated to make effective provisions for securing the rights to work, education, and public assistance, the obligation is watered down by the phrase, “within the limits of its economic capacity and development.” This provision suggests that PWDs deserve certain rights only if affordable to the State. According to Nordenfelt, “The very classification of a person as handicapped presupposes an ethical or political decision” (Nordenfelt, 2000, p. 123).

Thus, before the Persons with Disabilities Act of 1995 was passed, disabilities were primarily used in the Indian legal system to determine compensation for accidental injury and to bar people with disabilities from specific occupations. Space constraint does not allow me to deal with this issue any further. Analyzing some significant court decisions rendered during this period may help us gain some insight into the models of impairment used by the Courts at the time and to examine whether the same inhibited or shaped judicial approaches in any way.

Article 13 of the Constitution of India declares every State action and in certain cases even actions of non-State bodies to be unconstitutional if they are in breach of fundamental rights under the Indian Constitution. The mandate of this article has been strengthened by the advent of public interest litigation (PIL). PIL is a post-colonial instrument and can be invoked by any public spirited individual or social activist to vindicate the cause of vulnerable sections of society who would otherwise lack both resources and access to courts. PILs can be filed in both the Supreme Court of India and High Courts. In the context of disability rights, it is one of the most sought-after actions resorted to by activists to take up the causes of PWDs and to legally assert their rights. Considered against an ableist Constitution and status-quoist legal order, the response of the judiciary to these PILs is most commendable, particularly prior to the enactment of the PWD Act.

In *National Federation of the Blind v Union Public Service Commission* (1993), a young blind lawyer sought a direction from the Supreme Court of India to the Union Public Service Commission which would allow blind persons to take examinations with the assistance of a writer or by writing the papers in braille. The Court held, “If some of the posts in the Indian Administrative Service and other allied services, as identified by the committee can be filled from amongst the visually handicapped persons then we see no reason why they should not be permitted to sit and write the civil services examination” (*National Federation of Blind v Union Public Service Commission*, 1993, para 13). However, the court qualified this by pointing out that, once recruited to the lowest level of the service, the visually impaired person should have no right to claim promotion to a higher post if that particular post was not suitable for them. While implementing this judgment, although the Union Public Service Commission recognized the entitlement of blind people to the assistance of writers, it withdrew the choice given to blind persons by the court to write the answer in Braille – on the ground that this would make it impossible for examiners to distinguish between the scripts of different blind persons.

Another case concerned the refusal by the State Government of Orissa to provide financial assistance and recognition to a school for deaf and people with speech impairment on the ground of financial incapacity. The Orissa High Court in *Ramchandra Tandi v State* (1994) held that the decision of the state, based on financial instability and austerity, was untenable. Allowing the petition, the court held, “After nearly half a century of independence, it does not befit the State to take plea of unsound financial condition to deny meagre amounts needed for a few ‘deaf and dumb children’ ” (Ramchandra Tandi v. State of Orissa (1994 *SCC OnLine Ori 29 Para 5*).

Although the courts do not specifically mention any disability rights models in these two cases, a detailed examination of the judgments reveals that the judges were swayed by the “partial essentialist individual deficit approach,” a variant of the medical model discussed above. In these cases the Courts also supported the human agency of Persons with disabilities and anchored the idea of disability in the fundamental rights of Part III of the Indian Constitution.

In sharp contrast to these two cases, where the court was able to uphold the rights of disabled people by recognizing the State’s correlative obligation, were several other cases decided during this time period. Thus, as discussed by Dhanda (2002, pp. 92–93 (drawing on news article in the *Times of India*, 29 June 1994, p. 6)), the Bombay high court failed to find any *malafide* in a state government’s decision to allow large-scale hysterectomies of girls with intellectual disabilities residing in institutions, where notice was issued to the State by the court but the case did not progress.

This case is a textbook example of the "full essentialist individual deficiency" interpretation discussed above. The decision of the State was clearly actuated by the possibility of women with intellectual disabilities remaining pregnant after they had been sexually abused by the employees of the institution.

In other cases relating to the administration and proper management of the mental asylums of Agra, Ranchi, Gwalior, and Shahadra such as *Rakesh Chandra Narayan v State of Bihar* (1989), *S.R. Kapoor and Others v Union of India and Others* (1990), *Supreme Court Legal Aid Committee v State of M P and others* (1995), *Aman Hingorani v Union of India* (1995), separate petitions were filed and the Court gave almost the same recommendations in each of the cases. According to Dhanda, "In such cases the Court should have suo moto taken suitable actions and issued proper directions to each of the mental hospitals within the country to abide by the court's guidelines and also instruct the respective governments to take necessary steps to initiate changes" (Dhanda, 2005, pp. 376–377).

The cases from this era thus demonstrate the courts' tendency to adhere to the medical model of Disability, treating impairment as an irreparable deformity and thereby leaving the fate of persons with impairments to the discretion of the State. However, in some cases, the courts were able to anchor Disability rights in values of equality and fairness set out in the fundamental rights of Part III of the Indian Constitution, thereby bringing about some systemic transformation. Surprisingly, Courts have been able to accomplish the same in the teeth of very ableist Constitutionalism and the absence of any legislation.

The Persons with Disability (Equal Opportunities Protection of Rights and Full Participation) Act of 1995, passed in response to the First Asia Pacific decade of Disability (1993–2002), by the Parliament of India, did not significantly alter the legal environment. By defining disability in terms of the severity of physical impairments, Parliament endorsed the medical model. However, the law was also influenced by the part essential individual deficit interpretation, a moderate variant of the medical model discussed above.

The case law in relation to this Act primarily concerned the dismissal of employees who had acquired disabilities whilst in the employment of the State or one of its agencies, and the implementation of job reservations for PWDs in public employment. However, courts also delivered some judgments, influenced by the part essentialist individual deficiency approach, concerning the State's obligations under sections 30, 38, and 42 of the Persons with Disabilities Act 1995 to initiate and evolve schemes and programs for the realization of positive rights. Courts are required to step in should the State fail to formulate such schemes in order to prevent them becoming merely discretionary (Sikri, 2004).

Javed Abidi v union of India (1999) I is one such case. Along with the general enforcement of the persons with Disability Act 1995, the petitioner in this case also sought directions to provide aisle chairs in every aircraft and install ambulifts in all airports. It was also argued that discounted Airfares should be extended to people with other types of disability besides blind people. Playing down this argument, the Court held that enforcement of this law was contingent on economic capacity, and found that wholesale extension of concessionary air travel was implausible. But, emphasizing the severity of other impairments, the court directed the airline to extend discounted airfares within the country to people with “locomotor disabilities” of 80 or higher percentage (*Javed Abidi v Union of India* (1999) 1 SCC 467, Para 5). In response to this ruling, Indian Airlines agreed to offer ambulifts and aisle chairs to passengers with disabilities at all the airports in a phased manner.

Disabled Rights Group v Chief Election Commission and others (2004) was a public interest litigation seeking directions to the State to provide an enabling environment, by way of ramps, disabled-friendly voting machines (EVMs), security measures in the polling booths, and identification of their disability status in the electoral rolls, for casting votes by PWDs in various general and local elections. The Supreme Court ordered the Chief Secretaries of all the Indian States to coordinate with the Election commission of India to ensure installation of wooden ramps to make polling places at least in cities and metropolitan areas accessible for PWDs.

Fifteen years from the date of this judgment, there has been structural change in the policy of the Election commission of India, with repeated emphasis now being placed on the accessibility of polling booths and allied facilities. This has been possible due to sustained cause lawyering through a series of petitions demonstrating the influence of the social cum human rights model of Disability.

In *National Association for the Blind and Others v Central Board of Secondary Education and Others* (2001) and *Dhaval S Chotai v Union of India and others* (2003), the Delhi High Court and Bombay High Court respectively acceded to the contentions of students with visual impairment and cerebral palsy to provide extra time for writing examination papers. Due to paucity of time, the Delhi High Court did not allow an additional claim in respect of modification of the mathematics paper and supply of question papers in Braille. However, the court directed modification of the curriculum and examination system, in light of the objectives of the Act.

In *Anka Toppo v AllMS* (2001), a final year MBBS student upon sudden loss of sight when not allowed by College Authorities to appear in the examinations, moved the National Human Rights Commission of India. The college defended its action by contending “in view of the severe visual loss suffered by Shri Toppo. It would not be possible for him to work in the medical profession.” However, after considerable persuasion by the National Human Rights Commission of India and upon furnishing of numerous examples of blind people successfully pursuing medical practice, the college finally agreed to allow the petitioner to appear in the examination for the MBBS course with appropriate modifications. Against the backdrop of this case, the National Human Rights Commission recommended to the Medical Council of India (the Apex Body governing medical education in India) to fine tune and tailor its policy for providing the same facility and system for students in such conditions in other medical institutions of the country as well. (*Anka Toppo vs AIIMS*, No.1754/30/2000–2001).

Given that the above cases were decided before the ratification of the UNCRPD by India and the narrow scope of the Persons with Disabilities Act of 1995, the influence of the medical model of disability and a profoundly ableist constitutional framing, the approach taken by the judiciary in these cases is remarkably progressive in advancing the rights-based approach. Prima facie the jurisprudence evolved by the

Courts thus far seems to be confined to particular controversies or responses to individual case. However, a close look on the impact of these decisions demonstrates that both at the time of their pronouncements and in terms of their impact on policies and structures of the State, the same deserve the tag of "change makers." With the pronouncement of the National Federation of the Blind decision in 1994, more than 100 individuals with different disabilities have been permitted entry into the higher echelons of Indian bureaucracy, thereby seriously contesting myths about the unproductivity of people with disabilities. A number of professional bodies, such as the Institution of Charted Accountants, have tailored examination procedures so as to incorporate provision for reasonable accommodations for people with disabilities. Thus, the impact of this jurisprudence is much ahead of its time in espousing the socio-cum-human rights model of Disability, albeit implicitly.

In 2006 the UNCRPD was adopted by the United Nations. India became one of the first signatories of this convention and later in that year also categorically ratified the same. However, the Disability Rights Movement had to wait another 10 years for concrete action in the form of legislation making the convention part of the Indian legal order. During this time, the Judiciary continued to deliver a number of important pronouncements. In a significant study, Dr. Atrey shows that, from the date of ratification of the UNCRPD by India to the enactment of the Rights of Persons with Disabilities Act 2016, the Supreme Court and High courts referred to the UNCRPD in 28 cases, but only twice (*Jeeja Ghosh v. Union of India*, 2016; and *Vibhu Dayal Sharma v. Director High Court of Punjab and Haryana*, 2013) made an explicit reference to models of disability rights. In none of the cases was contemporary disability rights scholarship alluded to.

The Delhi High Court, in *Javed Abidi v Union of India and others* (2008 unreported) II, while dealing with the issue of inaccessibility of public buildings under section 46 of the PWD Act 1995, made relief subject to the conditionality of the economic capacity of the State. In other words, the right to accessibility was enforceable only as far as it was affordable to the state, bringing into play the "part essentialist individual deficiency" interpretation.

Unexpectedly, courts did not draw on the UNCRPD in most of these judgments. To illustrate, unlike *Javed Abidi I* in 1999, where the Supreme Court had only partially accepted the defense of economic capacity when providing relief to people with severe locomotor disabilities, in *Javed Abidi II* the Delhi high court simply accepted uncritically the State's arguments based on financial constraints without weighing them against obligations under the UNCRPD.

In the next section, judicial discourse explicitly referring to the socio-human rights model of Disability is analyzed.

Socio-human Rights Model of Disability in Judicial Discourse Post RPWD Act 2016

This section explores how the Supreme Court of India and High Courts of various States have developed jurisprudence in light of socio-human rights models of disability for the amelioration of the lives of people with disabilities. It focuses mainly on cases decided after the enactment of RPWD Act 2016, by drawing on the MANUPATRA and SCC data bases. Supreme Court and High courts mentioned the UNCRPD in 13 cases between December 2016 and December 5, 2022, with eight of those judgments making reference to the socio-human rights model. It is important to examine these cases to determine whether such references were merely rhetorical or whether they resulted in a paradigm shift in the conception of disability or structural change.

In *Vibhu Dayal Sharma*, the pertinent question before the Punjab and Haryana High court was whether cancer should be considered as a disability with in the definition of persons with disability under the PWD Act 1995. The court assumed that conditions like cancer with their "adverse impact" on the life course of such people "can medically qualify as disabilities" in a broad sense and that they would therefore meet the criteria of "impairments" for purposes such as reservation in educational institutions. However, the court declined to follow this course of action, holding that this was an issue of public policy and as such was not one for the court to decide. Accordingly it disposed of the case with the hope that, during the revision of the 1995 Act, the legislature would enlarge the scope of the definition of Disability to cover such conditions in line with the UNCRPD (Para 17), observing that "The UN Convention had adopted the social model of disability and recommended to the signatories of the Convention to define disability as including those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (Para 11).

A careful analysis reveals that the court here offered valuable guidance to the Legislature, urging it to extrapolate the legal propositions from the mandate of the UNCRPD and Social model of disability (*Vibhu Dayal Sharma v Director and others*, 2013). As a consequence, the Indian Parliament added 14 additional impairments or health conditions to the pre-existing seven, thereby introducing a significantly broadened definition of disability through the RPWD Act 2016.

A Public Interest Litigation was filed in *Pramod Arora v Hon'ble Lt. Governor of Delhi and Ors.* (2014) to uphold the right to education of Children with disabilities under Section 26 of the PWD Act 1995. It was argued that the amendment to section 2(d) of the Right to Education Act 2009 put disabled children at a disadvantage by defining "child belonging to disadvantaged group" as including disabled children. As a direct result of this amendment, disabled children would have had to compete within the 25% quota earmarked for the general category of "child belonging to disadvantaged group" under section 12(l) of the Right to Education Act – instead of benefiting from a distinct and separate 3% quota guaranteed under section 39, read with section 26, of the Persons with Disabilities Act 1995 which required free education in an appropriate environment to be granted to disabled children, in order to facilitate their integration. According to the petitioners, the values of accessibility, integration, and an enabling environment – instantiated in Section 26 of the Persons with Disabilities Act 1995 – would be undermined if disabled children were uncritically segregated within the category of "Children belonging to disadvantaged group." They therefore pressed for implementation of a separate 3% quota for Children with disabilities, across all schools in the National Capital Territory of

Delhi (NCT) and sought effective compliance with obligations to implement the right to inclusive education, including the upgrading of infrastructure to include appropriate modifications and the readiness of schools to address the needs of disabled children in accordance with the UNCRPD. After reviewing relevant constitutional and statutory provisions, the Court expressed its dissatisfaction at the appalling standards of admitting and integrating children with disabilities in primary schools and directed NCT to desegregate its 25% quota so as to create a sub-classification for children with disabilities, assuring that their right to a 3% reservation would not be diminished. An elaborate admission and reporting process for disabled children in primary and first grade classes was also recommended by the court. Importantly for current purposes, the court cautioned against viewing Disability rights through the lens of "Medical and charity models" and opined that

> The social model, on the other hand, views disability as the product of pre-existing barriers created by society. Education is therefore the first step for breaking down these barriers, which prevent full and meaningful participation of persons with disabilities in the processes of life and mainstream of society. . . .Though a small minority (2.1% of the population), they deserve no less than the rights under the Persons with Disabilities Act 1995 and the Right to Education Act 2009. It is time all concerned stop viewing those with disabilities as ill and incomplete and instead help them take hold of their lives. (Para 63)

This is therefore one of the landmark decisions which, although pronounced before the RPWD Act 2016, categorically demonstrates the capacity of the courts to inject the spirit or values underlying the UNCRPD into an Ableist legislative framework. Following this case, the Supreme Court heard a series of Public interest litigation cases which pressed for recognition and enforcement of rights to accessibility and reasonable accommodation in Educational institutions (*Rajive Raturi v. Union of India,* (2018) 2 SCC 413, the litigation is ongoing). The court has also issued a slew of directions to secure enabling environments and appoint resource teachers in educational institutions to enforce the right to education of children with disabilities (*Rajneesh Kumar Pandey v. Union of India*, 2021 SCC OnLine SC 1143, the litigation is ongoing).

In these cases, although the socio-human rights model is not explicitly referenced, it is clearly foregrounded in the approach of the court.

In *Vikash Kumar vs. UPSC* (2021), the question before the Supreme Court was whether "a student with writers' cramp" was entitled to the assistance of a scribe to write an examination. The Union Public Service Commission contended that assistance of a scribe was an entitlement only for persons with disabilities recognized in the RPWD Act under the rubric of benchmark disabilities. After perusing the relevant provisions of the RPWD Act 2016 and UNCRPD, however, the Court rejected this argument and directed the authorities to allow him to write exams with the help of a scribe. The Court held that the RPWD Act had carved out a particular context for the category of benchmark disability to come into play and cannot have been unduly expanded to whittle down the scope of overarching principles underlying the RPWD Act, 2016. It also held that, because the principle of reasonable accommodation is a threshold for the attainment of disability equality, its ambit could not be cut down to apply only in respect of benchmark disabilities. In fact, the court read this principle as an equality-enabling and justice-individualizing concept. It supported this reasoning by referring to the social model of disability. According to it, the RPWD Act 2016 has a more inclusive definition of "persons with disability" evidencing a shift from a stigmatizing medical model of disability under the 1995 Act to a social model of disability which recognizes that it is societal and physical constraints that are at the heart of the exclusion of persons with disabilities from full and effective participation in society.

In order to give teeth to this observation, the court directed the Union Public Service Commission to formulate a revised scribe policy. In response to the judgment, the Department of Disability Affairs in the Government of India has issued Guidelines for conducting written examinations for persons with specified disabilities falling within the definition of Section 2(s) of the RPwD Act 2016, but not falling within the definition of Section 2(r) of the said Act – i.e., persons having less than 40% disability and having difficulty in writing

https://disabilityaffairs.gov.in/upload/uploadfiles/files/Vikash%20Kumar%20Guidelines%2010-8-22.pdf
http://disabilityaffairs.gov.in/upload/uploadfiles/files/Guidelines-29_08_2018.pdf
http://disabilityaffairs.gov.in/upload/uploadfiles/files/Corrigendum-08-02-19.pdf

In *Ravinder Kumar Dhariwal vs. Union of India* (2021), the Supreme Court considered the legality of the suspension of an Assistant Commandant on grounds of misconduct and "mental disability" under the Persons with Disabilities Act 1995. The petitioner had a history of receiving continuous treatment for "obsessive compulsive disorder, secondary major depression, and bipolar affective disorder" since 2009. He alleged that he was continuously posted in insurgency areas for years together as a consequence of which, he developed "mental disorders" in 2008. The Central Reserved Police Force department, instead of applying Section 47 of PWD Act 1995 mandating alternative employment in case of acquiring disability during service to his case, suspended him from his duties in 2010.

The Court opined

> While a causal connection may need to be established between the ground for discrimination and the discriminatory act, it is not required to be shown that the discrimination occurred solely on the basis of the forbidden ground. As long as it can be shown that the forbidden ground played a role in the discriminatory action, the action will violate the guarantee against non-discrimination. (Para 116)

Extending the above law to the disability context, the court observed that

> A person with a disability is not required to prove that discrimination occurred solely on the basis that they had a disability. Disability needs to be one of the factors that led to the discriminatory act. Thus, in the present case, the appellant is only required to prove that disability was one of the factors that led to the institution of disciplinary proceedings against him on the charge of misconduct. (Para 119)

Highlighting the facts of the instant case, the court opined that

> An interpretation that the conduct should solely be a result of an employee's 'mental disability' would place many 'persons with mental disabilities' outside the scope of human rights protection... The over-emphasis on the choice or agency of a person with a mental health disorder furthers the stigma against them." (Para 120)

Evidence does not support the indiscriminate association of "mental impairment" with violence or the notion that someone with a "mental disability" is a danger to society. Therefore, a complex and customized approach to discrimination claims based on "mental impairments" is necessary, with a focus on the disadvantage resulting from the same.

The Court opined

> a person with a mental disability is entitled to the protection of the rights under the RPWD Act 2016 as long as they meet the definitional criteria of what constitutes a 'person with a disability' under Section 2(s). Having regard to the complex nature of mental health disorders, any residual control that persons with mental disabilities have over their conduct merely diminishes the extent to which the disability contributed to the conduct, it does not eliminate it as a factor. (Para 123)

The Court critiqued the Social construction of disability by observing, "Disability, as a social construct, precedes the medical condition of an individual. The sense of disability is introduced because of the absence of access to facilities" (Para 34).

The Court articulated the idea of full legal capacity by invoking the socio-human rights model of disability and the UNCRPD and by drawing from General Comment 1

> In order to fully recognise the 'universal legal capacity' where all persons inherently possess legal capacity regardless of disability or decision-making skills. They may however be provided with support (and not substitution) to exercise their legal capacity. This shift from the substituted legal capacity model to the supported legal capacity model is important for recognition of the agency of disabled persons and adoption of social model of disability. (General Comment 1, Para 25)

On the strength of the spirit of General Comment 1, the Court inferred, "the recognition of the legal capacity of persons with psychosocial disabilities confers on them legal personhood, where they can be a bearer of rights and exercise those rights" (Para 59).

The Court held that as the appellant had been receiving treatment for mental health disorders for a long time since 2009 and diagnosed with 40–70% of permanent disability by a government hospital, he was more vulnerable than non-disabled people to engage in behavior that could be classified as misconduct because of his mental disability. In such circumstances, his interests must be protected against both direct and indirect discrimination. Accordingly, the court set aside the proceedings as discriminatory on the ground of disability, in violation of the RPWD Act, and afforded him the reasonable accommodation by directing the respondents to assign him an alternate post not involving the use of or control over fire-arms or equipment which may pose a danger to the appellant or others in or around the work-place. A careful analysis of this case demonstrates that the court has deployed the socio-human rights model of disability – along with UNCRPD doctrines, standards, and principles such as Reasonable accommodation – not only to transform the life of the petitioner, but also to improve the service conditions of the Central Reserved Police Force and set up new benchmarks by which to influence engagement with similar future cases.

The Court has also drawn on the socio-human rights model to move away from the ableist view that persons with "Mental health conditions" pose a danger to society. In a ground-breaking judgment, *Bhavya Nain v High Court of Delhi* (2020), the Delhi High Court actively responded to Vikash Kumar by rejecting the arguments made by the Administrative side of the Delhi High Court for the disqualification of a person who was bi-polar from holding the office of a judge. Although the court did not cite the UNCRPD or explicitly refer to the social or human rights models of disability, it infused the spirit of the same into its reasoning. It observed that:

> The mere apprehension that the respondent has – that the petitioner may not be able to handle the responsibility and stress which a Judicial Officer faces, cannot be a reason to declare him medically "unfit", or to say that he is not entitled to claim reservation. There is no medical opinion placed on record, or considered by the respondent, to come to the conclusion that a person – who is suffering from BPAD, and is under remission, would not be able to discharge his responsibilities as a Judicial Officer. Pertinently, there is no exemption granted by the appropriate Government referable to the proviso to Section 20(1) of the RPwD Act. (Para 53)

On appeal, in *Akanksha Singh v High Court of Delhi* 2020, the Supreme Court upheld this approach. This decision is highly significant as it busts the myth that disabled people are not eligible to serve as judges. Nevertheless, the fact that the judgment was extremely short represents a missed opportunity for the more explicit development of principles of disability equality and recognition of their importance.

The case of *Disabled Rights Group v Union of India* (2017) was based on a public interest litigation claim in which it was argued that directions should be issued to the State to implement a reservation in higher education institutions and secure an accessible and barrier-free environment for students with locomotor disability. The case entails ongoing court monitoring. The Court cast the arguments of the petitioners in the social model of disability, observing that

> The Social Model of Disability locates disability as being socially constructed through the creation of artificial attitudinal, organisational and environmental barriers. Impairment is regarded as being a normal part of the human condition, with everyone experiencing impairment differently and having different access needs. Life is accepted as including negative experiences, and impairment may be-but is not necessarily-one of them. Disabled people are defined as being people who experience the unnecessary barriers created by society within their daily life. Social Model of disability has gained ground in the international debate. This views disability as a social construct and emphasises society's shortcomings, stigmatisation and discrimination in its reaction to persons with disability. It

> distinguishes between functional impairments (disability) both of a physical and psychological nature, and the loss of equal participation in social processes that only arises through interaction with the social setting (handicap). These developments have contributed to a new (WHO) model, which bears in mind social as well as functional and individual factors in its classification of health and health-related areas. Keeping in view the above, proper facilities need to be provided to differently-abled persons while having higher education. (Para 11)

Thus, informed by the social model, the court required the University Grant Commission to consider the feasibility of setting up a Committee to frame “Guidelines for Accessibility for Students with Disabilities in Universities/Colleges”; for purposes of ensuring compliance with Section 32 of the Disabilities Act 2016 (which lays down a 5% reservation for Students with disabilities in Higher Educational establishments) and explore the feasibility of establishing in-house bodies within each Higher Education institution “for taking care of day to day needs of differently abled persons” as well as implementing Schemes devised by the Expert Committee (Para 17 (ii)). Since then, the court has issued numerous compliance orders. In March 2022 a committee, of the type envisaged by the Court, was finally established and charged with the responsibility of formulating policies addressing the issues raised in the petition. This case demonstrates the role of the social model as a change-maker and proves that, despite challenges, it is possible to secure accountability of stakeholders for the effective implementation of the RPWD Act 2016.

In *Shobha Gopalakrishnan v State of Kerala* (2019), the question before the Kerala High Court was whether, in the absence of any specific statutory obligation, Article 226 of the Constitution of India empowers High Courts to appoint guardians for persons in “comatose conditions.” Ruling that High Courts did have such a power, its judgment explicitly referred to the rights-based approach to disability and acknowledged its attendant paradigm shift in disability rights jurisprudence. In its words:

> The “rights-based approach” towards persons with disabilities came to be accorded by the U.N. Convention on the Rights of Persons with Disabilities, 2006, treating the lives of persons with disabilities as valuable as that of any other human being. It is pointed out that the Convention brought a paradigm shift in its approach and attitude towards disability, shifting from a model where persons with disabilities are treated as “objects of medical treatment, charity and social protection”, to the platform where they are recognised as persons with equal rights and a vested right of participation. Accordingly, the Persons with Disabilities (Equal Opportunities, protection of rights and full participation) Act, 1995 was repealed and the new Act-Rights of Persons with Disabilities Act, 2016 (RPWD Act) was enacted. It was simultaneous to the enactment of the RPWD Act, 2016, that the old Mental Health Act, 1987 came to be repealed giving rise to the Mental Health Care Act, 2017 in tune with the norms of the U.N. Convention, whereby a “rights-based protection” was brought about for mentally ill persons. (Para 21)

This case is therefore another in which judges drew on the mandate of the human rights model of disability and the UNCRPD to address gaps in domestic law.

In *Jeeja Ghosh v Union of India* (2016), the Supreme Court severely criticized a private airliner for its insensitive treatment of the petitioner, who it had prevented from flying because of her cerebral palsy. The Court ordered the airline to pay her INR 10 Lacs by way of monetary compensation. In its judgment, the Court attributed the cause of the petitioner’s ill-treatment in the medical model of disability and cautioned against viewing disabled people as dependent, weak, or vulnerable. It observed that

> The subject of the rights of persons with disabilities should be approached from human rights perspective, which recognised that persons with disabilities were entitled to enjoy the full range of internationally guaranteed rights and freedoms without discrimination on the ground of disability. (Para 43)

This case has led to important new guidelines being issued by the Ministry of Civil aviation the "Harmonized Guidelines for Standards of Accessibility and Provision of facilities for Persons with Disabilities (Divyangjan) under the Rights of Persons with Disabilities Rules, 2017" (https://www.civilaviation.gov.in/sites/default/files/Accessibility-Standards-and-Provision-of-facilities-for-Persons-with-Disabilities.pdf).

In *M. Sameeha Barvin v Joint Secretary Ministry of Youth and Sports Department of Sports Government of India and Others* (2021), this paradigm shift in how disabled people should be treated was again recognized – this time by the Madras High Court. In its words,

> The RPwD Act is a paradigm shift from a technical model of disability carrying with it the heavy burden of stigma under the 1995, Act to a model of disability that encompasses within its fold physical, mental, intellectual, social, psycho-social and other barriers that accompany disability which lie at the heart of exclusion of the disabled from realising their full potential and participating in society as full and equal members and citizens as contemplated by the framers of our Constitution. (Para 27)

This case concerned the denial of opportunities to the petitioner, who was a female athlete with 90% hearing impairment, to participate in an international sport event organized by the World Deaf Athletics Championship in Poland. The Court held that the selection authorities' decision that she should not be part of the team because she would be the only woman was discriminatory. Invoking the principle of intersectionality, the court highlighted the vulnerability of women athletes with Disabilities and issued detailed guidelines to sports authorities which required them, among other things, to

> ensure that all the women athletes whether with or without disabilities, be given equal treatment on par with males, so as to enjoy full and equal rights and freedoms and to maintain their dignity. (Para 55(xii))

This case is significant because it highlights the importance of recognizing and promoting rights to recreation and participation in sports by women athletes with disabilities.

Conclusion

I have argued in this chapter that, against the backdrop of an ableist Constitution and a very narrow antidiscrimination legislative regime, the Indian judiciary has found ways to superimpose transformative jurisprudence by deploying the social and human rights model of disability, creatively invoking the UNCRPD and thereby facilitating a progressive interpretation of the PWD Act 1995 and RPWD Act 2016 (Jain 2021). Parliament's enactment of the RPWD Act 2016 has undoubtedly opened up more space for such judicial initiatives and thus played an influential part in the judicial recognition of a paradigm shift from medical to socio-human rights models of disability. In section "Disability-Rights Based Adjudication in the Pre-RPWD Act Era" above, I analyzed Court judgments which did not explicitly mention the Socio-human Rights Model of Disability; and in section " Socio-human Rights Model of Disability in Judicial Discourse Post RPWD Act 2016," I highlighted judgments which did explicitly mentioning the same. This division provides structure to the discussion and demonstrates the positive impact of explicit incorporation of the socio-human rights model of disability in judicial discourse.

Even before the enactment of the PWD ACT 1995, examples can be found of judges reducing the potential impact of the strongest version of the Medical model by drawing on the "part essentialist individual deficiency" interpretation discussed above. Thus, the *National Federation of the Blind case* (1993) led to the appointment of a number of disabled persons to civil service posts. Due to the absence of relevant data, it is not possible to provide exact figures for exactly how many disabled officers have been appointed over the subsequent 30 years (https://www.thebetterindia.com/187610/upsc-results-differently-abled-inspiring/, https://www.indiatoday.in/magazine/education/story/20060626-12-physically-challenged-candidates-clear-indian-civil-services-exams-785080-2006-06-25).

Nevertheless, it is clear that the approach to disability employment and opportunity within the civil service has become more positive (https://www.livemint.com/news/india/defying-disability-and-poverty-inspiring-stories-of-upsc-toppers-11653932165222.html).

Courts, while adjudicating individual claims, have at least on some occasions have invoked the social and human rights models of disability to address structural and systemic deficit by strengthening mechanisms for holding stakeholders accountable. This is clearly illustrated by the decisions in Viakash Kumar, Jeeja Ghosh, and Aravinder Dhariwal.

Analysis of adjudicatory practice since India's ratification of the UNCRPD and the enactment of the RPWD Act 2016 demonstrates how courts are able to factor in the social and human rights model of disability for empowerment of people with disability as a heterogeneous social group. Through disability rights adjudication, the Courts have infused the public law emotions of compassion and empathy into the Indian legal order. The values of equality, dignity, and personal liberty (underpinning Articles 14, 19, and 21 of the Indian Constitution) have been used implicitly and explicitly by courts to constitutionalize the rights of people with disabilities. The same has transformed the enforcement of socioeconomic rights by recognizing the State's positive duties to address the lingering and systemic disadvantages faced by disabled people. Examples of unhelpful or restrictive approaches can of course also be found in the judgments of courts tackling disability-related cases in India. Nevertheless, it is clear that the social and human rights models of disability have on occasion been used by judges in India to engage in some degree of judicial activism and thereby to advance the rights of Persons with disabilities. This is itself significant.

The need of the hour is to encourage such judicial efforts and to complement them with stronger measures to give effect to the concepts of respect for difference and human dignity which underlie the social and human rights models of disability. Such a mission cannot be accomplished merely with the passing of Laws. The State must also focus its attention on the development of institutions for evolving the rights-enabling conditions needed to secure compliance with such laws.

In conclusion, I allude to Robert M. Hensel's observation that "There is no greater disability in society than the inability to see a person as more."

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Disability Rights Advocacy in China: Inclusive Education, Civil Society, and Mobilizing Ideas

16

Yi Huang and Bo Chen

Contents

Abstract

This chapter examines the impact of the United Nations Convention on the Rights of Persons with Disabilities and the human rights model of disability on which it rests, on disability rights advocacy in China. It does so by presenting three case studies of initiatives to enhance inclusive education, each of which was led by a civil society organization using ideas rooted in the rights and principles of the Convention. Through a qualitative study into the campaigns led by registered parents' groups and unregistered grassroots disabled people's organizations, the chapter analyzes the various roles played by these actors and the strategies they used, highlighting critical factors relevant to promoting disability rights and social change in China.

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UNCRPD · Disability rights in China · Inclusive education · Civil society organizations · Disabled peoples' organizations · Human rights model

Introduction

Since the adoption of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2006, a growing number of scholarly and civil society research projects have emerged, with the aim of examining CRPD's impact and implementation in different state parties. This chapter is one such effort – with a particular focus on China. The implementation of disability rights in China has attracted particular interest. This may in part be because (as discussed in section "Background information") China has the largest population of persons with disabilities in the world. Also, as Stein (2010) points out, in comparison with the leading role it played in the drafting process, China has demonstrated a less progressive approach in advancing disability rights at the domestic level. Additionally, some interest in the implementation of disability rights in China may be generated by curiosity about experiences of and strategies for advocating for disability rights in a non-Western, non-liberal state which has significantly restricted the domestic space for international civil society (Huang, 2020). This chapter engages with such issues. It presents three case studies of how inclusive education, at various levels, has been promoted by civil society organizations, inspired by and using the rights and principles from the CRPD.

Of all the fields of disability rights addressed in the CRPD, inclusive education has been selected for attention here for a number of reasons. The primary one is that, as will be discussed below, advocacy for inclusive education in China has involved very diverse stakeholders, including individual persons with disabilities; grassroots disabled peoples' organizations (DPOs); groups of parents of children with intellectual disabilities; the general education system; the China Disabled People's Federation (CDPF) and its local branches; and educational departments of local governments. Given this diversity of stakeholders and the complex interactions between them, different actors have adopted varied strategies in their advocacy. The role of the CRPD in these strategies warrants examination. In addition, the highly contested practicality of inclusive education poses a global challenge to its implementation (De Beco, 2018), and reflection on Chinese experiences of advocating for inclusive education might well be useful to other advocates working in wider contexts.

Before tackling the case studies, section "Background information" will first outline some critical background information, including essential demographic data on persons with disabilities, the changing political environment for civil society, and brief development history of inclusive education in China. In doing so, the CRPD framework of inclusive education and the participation of persons with disabilities and their representative organizations in public decision-making will also be briefly explained. Then, section “Three campaigns for inclusive education in China” will present the case studies. It will describe three campaigns and discuss the common themes drawn from them. This will be followed by the conclusion.

Background Information

In this section, we will set out some essential geographical and demographic information. We will also lay out the political/social environment in China that civil society organizations (CSOs) in disability issues and DPOS have to work within and briefly introduce the development of inclusive education in China.

Demographic Context

China has the largest population of persons with disabilities in the world. The World Health Organization’s (2011) statistics indicate that 15% of the world’s population is disabled, though the Chinese government reported a lower percentage, namely, that only 6.34% of Chinese people have a disability (the Government of China, 2010). According to its initial report to the Committee on the Rights of Persons with Disabilities (CRPD Committee), over 80 million persons held disability certificates in China’s mainland (the Government of China, 2010). Statistics published by the International Labour Organization (2008) show that about 75% of these people live in rural areas, less than a million ever receive higher education, nearly half of them are illiterate, and only around a quarter are employed.

Closing Social Space for Disability Rights Advocacy

In the past decade, CSOs working in the field of disability and DPOs have experienced a firm shift from a comparatively open and accepting social environment to a highly restricted one for public interest campaigns and the growth of civil society. New laws have been enacted to restrict the activities of foreign CSOs in China and set a very high bar for Chinese CSOs and DPOs to receive funds from overseas (Huang, 2019). Due to the reality that most of the rights-advocating CSOs and DPOs were reliant on international funds to maintain their functioning, they were more seriously affected than service-providing CSOs and DPOs (Huang, 2020). This background is critical to the current study, as it demonstrates the challenges faced by the relevant CSOs and DPOs. It also helps to explain the fact that, in the current social and political context, surviving CSOs and DPOs very often have had to combine service provision and advocacy – the division of labor between idealists and realists, service providers, and rights advocates no longer being possible.

On the other hand, the CDPF and its connected associations for specific impairment types (e.g., China Association of People with Physical Disabilities and other associations of blind people, deaf people, people with intellectual disabilities and their relatives and friends, and people with “mental disabilities,” as used in Chinese and their family and friends) work directly with governments at all levels in developing and implementing disability-related law, policy, and service provision in China, playing a central role in disabled people’s daily lives (Committee on the Rights of Persons with Disabilities, 2011, para 148, 149; Zhao & Grotz, 2019). Claiming to be a national umbrella organization for the disabled, the CDPF has provincial, municipal, and local branches. The system of the CDPF and its local branches also represents the interests of the government which funds most of their activities and staff (China Disabled Persons’ Federation, 2016; Zhao & Grotz, 2019). It has been conceptualized as a “half government and half civil society” approach (Zhao & Grotz, 2019) or so-called government-organized nongovernmental organization (Hasmath et al., 2019). In some situations, the CDPF has the potential to be a strong advocate for disability rights and welfare, even where this entails challenging the government (Chen & Xu, 2011). Its role is less clear or promising in other situations, however, as illustrated by the case study described below.

This changing social/political environment poses a significant challenge to the implementation of Article 29(b) of the CRPD – which requires state parties to “[p] romote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs” through CSOs and DPOs and representation at all levels, including participation in the policy-making process on disability-related issues (required by Article 4(3)) and the monitoring mechanism of the CRPD (required by Article 33).

Inclusive Education in China

In the official Chinese version of General comment No. 4 on the right to inclusive education issued by the CRPD Committee (2016), the term “inclusive education” is translated into “bāoróngxìng jiàoyù” (包容性教育), which is seldom used in either academia or practice in China. More commonly used translations of inclusive education in academia are “rónghé jiàoyù” (融合教育) or “quánnà jiàoyù” (全纳教育). It is also worth pointing out that the most commonly used term in policies and among frontline teachers and administrators is “suíbān jiùdú” (随班就读), which could be directly translated into “learning in regular classrooms” (LRC). LRC has been commonly misunderstood as the primary method of achieving inclusive education in China, and many policy-makers and scholars use the terms interchangeably. Arguably, however, due to ongoing CRPD-related discussion, there is a growing understanding of the difference between the two. More problematically, in the official Chinese version of General comment No. 4, the term “rónghé” (融合) is used as the translation of both “inclusion” and “integration,” despite the fact that these terms have substantively different meanings in the context of inclusive education and disability rights in general. According to General comment No. 4, integration is the process of placing disabled students in mainstream educational institutions with the precondition that they can meet certain criteria, while inclusion requires an overall and systematic reform of the educational institution to embrace diversity and provide all students with a learning experience in accordance with their needs and preferences. It is worth pointing out that the term "rónghé jiàoyù" (融合教育) is commonly used by Chinese scholars to describe a situation in which disabled students are in mainstream school settings – the implications of which, for integration and inclusion, are often very unclear.

These differences in translation reflect how the idea and practice of inclusive education in China may be shaped and reshaped by the social, political, economic, and cultural conditions, in which the ideologies and values embedded in the CRPD have begun to take root. In the remainder of this section, we will review the development and current practice of education for disabled people in China, thereby providing important context for the three cases which will be discussed in section "Three Campaigns for Inclusive Education in China."

The beginning of modern education for disabled people in China was marked by the special schools funded by Western missionaries in the late nineteenth century. However, not until the 1980s did the Chinese government develop strategies regarding education for disabled people. Since the 1980s, the government has put most of its effort into establishing special schools. National statistics indicate that the number of special schools grew steeply from 292 in 1980 to 1539 in 2000, following with a relatively relaxed growth to 1706 in 2010 (An et al., 2018).

In 1985, the Ministry of Education, associated with several other governmental departments, published the Regulations on Admission and Graduation of Juveniles with Disabilities in Higher Education, requiring that higher education institutions should not reject disabled students if the impairments did not affect their ability to study, work, or live independently. Following this policy, some universities and colleges set up segregated entrance examinations for disabled students, wherein upon successful completion of which, disabled students could be enrolled on specific majors created for them (Deng et al., 2001).

The concept of LRC which, as explained above, has been used as the equivalent of inclusive education in China, was first adopted in 1986. This took place in a pilot project in which a number of students with visual impairments were integrated into regular classes (Gu, 1993). This project, to some degree, raised awareness of the fact that segregated special education is not the only way to provide education for disabled students. It is important to note, however, that the LRC was initiated neither in response to the idea of mainstreaming nor to promote inclusion. Instead, it was introduced to address the problem of making education available for disabled students, given the limited number of special schools at that time (Chen, 1997).

The Compulsory Education Law, enacted in 1986, was ambiguous as to whether it granted disabled students the equal right to public education. The law stipulated that all children beginning at age 6 must receive 9 years of free public education regardless of their "gender, race, ethnicity, family socioeconomic status, or religious belief." However, "all children," as defined in the law, did not include children with disabilities. The revised version of the Compulsory Education Law enacted in 2006 provided a clearer recognition of disabled children's right to education. The Law on the Protection of Disabled Persons, revised in 2008, explicitly required that regular schools should accept disabled students given that certain conditions were met; and

LRC was formally defined as a form of education available to disabled students. Further action was introduced by the Special Education Improvement Act in 2014 by the Ministry of Education of China, setting the goal of promoting inclusive education to ensure that all students with disabilities could receive an appropriate education. In the previous law and policies, disabled people's right to education had been essentially conditional on the ability of the individual student. The Special Education Improvement Act 2014 takes a step away from this approach, requiring capacity building of educational institutions, with a view to ensuring inclusion. The required measures for regular schools include establishing resource rooms with individualized learning materials, providing access to therapeutic equipment, and employing more teachers with experience in special education.

This change in the tone and direction of law and policy after 2008 reflects a more inclusive approach to education for disabled people. The fact that it was in 2008 that China ratified the CRPD suggests that the CRPD has been influential on relevant law and policy-making in China. However, these laws and policies are still not CRPD-compliant. For example, the Compulsory Education Law, as revised in 2016, states that regular schools should accept disabled students who have the capacity to receive general education, but it does not clarify who has the authority to make relevant capacity assessments nor how this should be done. The acceptance or rejection of disabled students by regular schools therefore becomes a rather arbitrary decision, which necessarily raises concerns about discrimination based on disability.

More significantly, current law and policy do not impose a clear obligation on regular schools to provide support for disabled students in processes for deciding on admission. The absence of such a legal obligation reinforces the notion that inclusive education is conditional and largely based on the severity of impairment and the individual's ability – an approach which contravenes CRPD's principles and requirements. Even those students who are included in regular schools are more often merely "sitting in the regular classroom" than learning or participating in the regular classroom, as in most cases there is no monitoring or evaluation mechanism on the quality of education provided to disabled students (McCabe, 2003).

In response to these issues, the CRPD Committee (2012) pointed out, in its Concluding Observations on China's initial report, that the large number of and continuing efforts in developing special schools are incompatible with the requirements of the CRPD. The committee further recommended reallocating resources from the special education system to promoting inclusive education in mainstream schools. The strategy at the national level, however, still puts emphasis on establishing more segregated special schools (Central Committee of the Communist Party of China, 2010). The government has proposed that special schools should serve as resource centers that provide both (a) education for students with severe disabilities and (b) support for regular schools for enhancing their inclusion of the majority of disabled students with less severe impairments.

However, such a dual system can hardly be justified under Article 24 of the CRPD. General comment No. 4 states clearly that inclusive education in the CRPD's context entails merging well-resourced segregated special education and general education to create "whole systems" (CRPD Committee 2016). Accordingly, without denying that the Chinese government promotes a more inclusive approach to education for disabled people than formerly the approach to inclusive education in China still deviates from the CRPD requirements. It can therefore be argued that law-making and government-oriented action to develop education for disabled people fails to demonstrate a clear commitment to fully implement Article 24 of the CRPD. Against this backdrop, the next section presents a case study of how CSOs and DPOs in China have attempted to narrow the gap by effective campaigns.

Three Campaigns for Inclusive Education in China

Aim of the Case Studies

This section reflects on three campaigns for inclusive education, focusing on the role played by the various CSOs and DPOs in promoting inclusive education and on how they used the CRPD. As explained above, the CRPD, and Article 24 in particular, has exerted only a limited influence on top-down law and policy reform on inclusive education in China. This section, however, demonstrates that it has been more influential on Chinese CSOs and DPOs. In this section, we present and analyze three campaigns in the form of case studies. We consider not only how the human rights ideas and principles in the CRPD have mobilized CSOs and DPOs in China but also how these CSOs and DPOs have mobilized the CRPD as a powerful tool in their advocacy for inclusive education.

The data used in the case studies have been collected primarily through participatory observation in these campaigns over the past decade. The names of the individual participants, CSOs, and DPOs will be kept anonymous. Due to the word limits of this short chapter, only a brief introduction to the campaigns led by the three CSOs or DPOs will be given, the focus being on common themes shared by the different campaigns.

General Information About the Three Campaigns

Case study A is an “LRC support program” initiated in 2008 by CSO A, an organization founded by parents of persons with intellectual disabilities or autism. This program was designed to provide special education assistant to disabled students who receive education in the form of LRC. Children of the founders of Organization A were the first to receive the service in question. After years’ pilot, CSO A managed to develop partnerships with educational experts and universities in its region, and this in turn has resulted in further rollout of the program – including through the training of more special education assistants; the provision of support to more students in the form of LRC; and the development of service evaluation and monitoring. Further advocacy by the parents’ group, CSO A, led in 2012 to the “LRC support program” being acknowledged by the local education bureau, which later agreed to fund it (albeit partially) from public monies. Interestingly, while CSO has A has developed connections with a wide range of stakeholders (such as local universities, mainstream schools, the local special education center, the media, and the local education bureau), the local CDPF is not part of the "LRC support program" network.

Case study B is another inclusive education pilot project. It was initiated in 2017 by CSO B, an association of parents of children with intellectual disabilities or autism. Unlike case study A, which started by providing a direct service to individual disabled students, case study B from the outset entailed a clear and definite vision of how the education system could be changed and made more inclusive. CSO B began this work by communicating the ideas, values, and principles of the CRPD, and Article 24 in particular, to parents, teachers, school administrators, and the local education bureau. It did this by providing training programs and submitting policy proposals. While CSO B did provide certain forms of support in individual cases, its primary focus was the independent evaluation and monitoring of the quality of education provided to disabled students. It also undertook to examine the degree to which relevant government departments had fulfilled their obligation of protecting and promoting disabled people's equal right to education. In doing so, CSO B has managed (impressively) to interact with schools and government officials in a manner which is more cooperative than critical. It has managed to empower the school teachers to offer more effective assistance to disabled students, support the pilot schools to mobilize their policies and funds in a more efficient way, and facilitate constructive dialogue between parents and government. Between 2018 and 2020, CSO B provided regular evaluation and monitoring of the quality of inclusive education in two mainstream schools and delivered training to 601 school teachers, which benefits 189 students with special education needs.

Case study C consists of a program of continuous policy advocacy for inclusive education carried out by DPO C – an organization formed by people with visual impairments. The first highlight was in 2014 when DPO C supported a massage therapist to take China's National College Entrance Examination (NCEE) in Braille. This was the first time a blind person managed to take the mainstream college entrance examination in Braille instead of simply taking the segregated entrance examination for disabled students. From its foundation, DPO C has been dedicated to identifying and removing different forms of discrimination against disabled people in education. Other examples of its work include initiating or participating in strategic litigation, applying for the Disclosure of relevant Government Information, calling for antidiscrimination scrutiny of existing policies, and submitting policy suggestions to responsible government departments. In contrast with CSO B, DPO C's interaction with the government has been more critical – grounded on the clear objective of reforming discriminatory policies that impede the realization of disabled people's equal right to education. As a result of a range of advocacy initiatives demanding reasonable accommodation in NCEE in 2014, a national policy was introduced the following year which expressly adopted this obligation. In contrast with CSO A, DPO C did not provide any direct service to individual disabled people.

Although these three case studies occurred at different times and in different contexts, our analysis identifies several common themes relating to the role played by the CRPD in each of them. The common themes, all connected to the CRPD and the human rights model concern the awareness of the equal rights of each individual with disabilities, how to turn from personal needs into public issues, and becoming experts in disabilities by lived experience.

Awareness of the Equal Rights of Each Individual

The CRPD has been described as "a catalyst for change" that enshrines a "paradigm shift" away from seeing disabled people as the "objects of charity, medical treatment and social protection" to recognizing them as "subjects of rights" (Arbour, 2006). The experience of CSO B and DPO C suggest that the CRPD and the "paradigm shift" it represents provide a radically new human rights framework for disabled people and their parents to promote the view that a disabled person is an individual with equal rights.

Inspired by the motto "nothing about us without us," DPO C was one of the grassroots DPOs formed after China ratified the CRPD. The formation of DPOs such as this is an example of how the human rights ideas and values underlying the CRPD have mobilized disabled people to rethink their identities and experience based on a novel human rights framework. Before DPO C's prominent work in 2014, the segregated college entrance examination for disabled students had long been the generally accepted norm and indeed was even treated as a measure through which to promote disabled people's access to higher education. Based on the idea of substantive and inclusive equality, underpinning the CRPD and elaborated by the CRPD Committee (2018), DPO C questioned this widespread understanding of "segregated but equal," by highlighting the barriers facing a blind person who wished to take the mainstream college entrance examination. It also vernacularized the concept of reasonable accommodation by demanding that exam papers should be provided in alternative formats.

A turning point in this case occurred when the public knew that the blind person had submitted blank answer sheets for two of the four subjects. This was because the blind person was not fluent in Braille and the examination body had refused his application to take the examination in an electronic format – which would have been an accommodation of his needs – rather than in Braille. That said, the blind person concerned and DPO C both faced enormous criticism from sighted people and blind communities. Despite this, DPO C maintained its clear position that, as an important component of the right to education, a disabled person must be provided with an equal opportunity to take the college entrance examination and that reading and writing an exam in an alternative form is neither a privilege nor a waste of public resource but rather a measure required to guarantee the substantively equal enjoyment of the right to education. DPO C's approach is thus a solid stand based on the human rights framework derived from the CRPD. To what extent the controversy created could have been avoided by an improved dialogue within the disability community is an important point of discussion (Ma & Ni, 2020). At the very least, however, this case illustrated that the CRPD and the human rights model of disability had an evident impact on mobilizing DPO C to reframe the experience of disabled people. In this process, the international human rights framework is transposed in the local context to strengthen the proposition made by disability rights advocates.

The human rights ideas and values underlying the CRPD have also provided a new way of thinking to parents of disabled people. Before CSO B was established in 2015, most parents of disabled people did not know about the CRPD, neither were they familiar with the human rights approach. In the context of education, for example, studying in mainstream schools was accepted by parents to be available to children with disabilities only if certain preconditions were satisfied – as something which was conditional rather than a basic right based on the principle of equality. Parents whose children had been admitted to mainstream schools tended to regard it as a favor or privilege bestowed by the school and thus that it was important for them to do everything possible to convince the school that their child would not cause any trouble. Some parents resorted to services, such as the special education assistants provided by CSO A, as discussed above. For parents unable to afford such services, however, many train themselves to be the “shadow teacher” or support teacher and accompany their children in school.

When CSO B was established in 2015, systematic training in the CRPD was part of its training package for parents of disabled people. Such training was rare at that time, as most training for parents then focused on rehabilitation. By offering training in the CRPD, CSO B aimed to convey to parents, from the outset, the idea that “we are not asking for a favor but a right to which our children are entitled.” Feedback from the training showed that such awareness-raising made parents realize that the enjoyment of rights should not be conditional on their child’s ability. It also gave them a new frame which redefined their role – from that of solver of all problems caused by their child to that of advocate for their child’s equal rights. This illustrates how the human rights ideas and values in the CRPD mobilized CSO B – which also repackaged these ideas in culturally resonant wrappings for presentation to parents of disabled children.

It is important to note that the human rights ideas also raise parents’ awareness of the subjectivity of their children. It provides the parents with a framework to understand that their willingness and preference may be different from that of their children and reflect on the difference between being a supporter and a substitute decision-maker of their children. As the children are growing up, some of the parents have shown the awareness that they should not only speak for their children but also empower their children, as a supporter, to speak for themselves.

From Personal Needs to Public Issue

As has been widely pointed out, there has been a longstanding tendency to understand disability as an individual problem or personal tragedy (Swain & French, 2000). This has resulted in a tendency to respond to the problems faced by disabled people by way of tackling a personal need rather than as a social or public issue. The early stages of case study A illustrate how this sort of understanding influences strategies adopted to fulfil disabled people's needs. The "LRC support program" in case study A was initiated because the founders of CSO A learned from the experience of their children that disabled students who receive education in the form of LRC may need additional personal assistants. They therefore mobilized their personal resources to provide such support, in the form of the special education assistants, for their children. Resorting to personal resources rather than public social support has been a common reaction, particularly among the parents of disabled people, to the reality that only limited social resource was allocated to address the needs of disabled people.

The CRPD provides a human rights framework which transfers the disability issue from the private sphere to the public domain. It, first of all, echoes the social model of disability by demonstrating clearly that disadvantage and exclusion should be attributed, not solely to one's impairment but to the interaction between the impairment and various social barriers. By stipulating that state parties must remove the social barriers faced by disabled people, the CRPD requires that responding to disabled people's experience and needs should be a public issue entailing the engagement of diverse social actors and sources. Moreover, particular rights (such as the right to inclusive education under Article 24) are elaborated together with examples of key obligations imposed on state parties, thus providing implementation guidelines for how it should be tackled as a public issue. This human rights framework has provided new critical perspectives for people with disabilities, parents, and relevant CSOs, prompting a redefinition of disabled people's experience of social barriers as a public issue and reshaping their strategies for removing such barriers. In case study A, for example, CSO A, instead of limiting its efforts to action within the resource of parents involved in the organization, started making changes to the "LRC support program" by engaging with a wide range of social actors and resources, including local government.

Compared to the gradual change evident in case study A, case study B represents a more radical approach to the promotion of inclusive education. When CSO B initiated its "pilot project on inclusive education" in 2017, the fact that there had been continuous training in the CRPD since 2015 meant that CSO B's leader and its parent representatives were already familiar with a human rights approach. Accordingly, CSO B was able to develop a clear vision of disabled people's rights to inclusive education as a public issue calling for the commitment of a wide range of social actors and resources. Accordingly, in situations where disabled students in mainstream school settings need personal assistants, CSO B does not attempt to provide the services needed but instead supports parents to compile their applications for personal assistance from relevant schools and works with parents to ensure that responses from schools are effective. CSO B has also established long-term collaborations with several schools – which it supports to develop relevant policies and funding models, as well as to develop good practice and expertise in inclusive education among school teachers. In addition, CSO B has carried out periodical independent evaluations of the implementation of relevant local policies and monitoring of the quality of education delivered to disabled students. The results of these evaluations and monitoring sessions have been submitted to the local education bureau, thereby serving as evidence for further policy reform and advocacy.

The inclusive education promotion strategy adopted by CSO B demonstrates its commitment to facilitating communication between not simply individual parents and school administrators but also the association of parents who advocate for the rights of their disabled children and representatives of the education system. It further illustrates how, at the same time as parents of disabled people are using CRPD's human rights framework to argue that disability-related barriers are a public issue requiring social change, CRPD's human rights framework also operates on the parents themselves – transforming them into a powerful force involved in public issues more broadly.

Being Recognized as Disability Experts

Scholars working in disability studies, particularly from an emancipatory perspective, have long recognized the importance and value of expertise derived from lived experience (Löve et al., 2017). However, in the social context of China, lived experience of disability has slightly counted for. As all three case studies suggest, however, the principles and values underlying the CRPD can operate to increase the importance of lived experience and empower disabled people and their parents to play more active roles in disability-related public issues.

DPO C has dedicated itself to promoting inclusive education through some relatively radical strategies – such as applying for Disclosure of Government Information and demanding antidiscrimination scrutiny of existing policies – which are not always welcomed by the government. However, these strategies have led to some meaningful communication and engagement with government. One of the key factors differentiating DPO C from politically sensitive human rights advocates is that it utilizes the CRPD as the theoretical and normative framework for its policy advocacy. Instead of just complaining about the social barriers faced by disabled people, DPO C articulates such complaints in the form of clear propositions, explaining carefully how these relate to China's obligations under the CRPD. This grounding also enables it to draw on the lived experience of disabled people to express their views and perspectives and to offer the government practical suggestions for policy reform. This effective blending of lived experience of disability and familiarity with CRPD's human rights framework is what gives DPO C its distinctive expertise.

Similar observations can be made of the experience of CSO A and CSO B. For both, the CRPD provides a framework for parents to theorize their experience of being the parents of disabled children and reflect on policies which affect them. This framework also empowers them to do more than simply articulate the needs of disabled people and their families – it enables them to engage in constructive dialogue, represent themselves rather as the substitute of their children, with government and other public bodies. Once the experience of being parents of disabled children is valued as a kind of expertise, they are in a position to drive forward, from the grassroots level, human rights ideas and values, and to promote the implementation of the CRPD in the local context.

Conclusion

In this chapter we have presented three case studies of campaigns for inclusive education in China. The campaigns were led by different organizations which adopted a range of approaches, but each of the campaigns was influenced and made possible, in significant ways, by the principles and human rights ideas of the CRPD. These case studies suggest that in China to date, the impact of the CRPD and the human rights model it promotes has been more apparent on civil society organizations, including disabled people's organizations, than on government and the CDPF system. This is unsurprising and likely to be in line with developments in other state parties. Yet, the impact of this human rights model on civil society actors and the campaigns they lead is an interesting subject worthy of further attention. We suggest that, inspired by the CRPD, civil society and disabled people's organizations have demonstrated and promoted increased awareness of a human rights model of disability. They are successfully using this idea, and the commitments made on ratification of the CRPD, to further shift perceptions of disability – away from being a private matter, to be addressed by the individuals themselves and their families, to being a public matter with implications for policy and public resource. In this process, there appears to emerge increasing respect for expertise based on lived experience. However, whether there would be a better appreciation of the value and importance of actively involving disabled people and their organizations in relevant reform processes requires further observation.

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The African Disability Protocol: Toward a Social and Human Rights Approach to Disability in the African Human Rights System

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Dianah Msipa and Paul Juma

Contents

Abstract

The adoption of the Protocol to the African Charter on Human and People's Rights on the Rights of Persons with Disabilities in Africa marked a pivotal juncture in the shifting approaches to disability in the African human rights system. The African Disability Protocol abandoned the medical and charity approaches to disability that are dominant in many of the preexisting African human rights instruments, in favor of a social and human rights approach to disability. This chapter argues that the unique lived experience of persons with disabilities in Africa dictated the shift from viewing disability in light of the medical model of disability to perceiving it as a human rights issue. Prior to the adoption of the Protocol, African human rights instruments had failed to translate into real change in the lives of persons with disabilities, making it necessary to reevaluate the approach to disability in the African human rights system. The process of rethinking approaches to disability did not take place in a vacuum.

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Global trends encapsulated in the Convention on the Rights of Persons with Disabilities had an enormous influence on this process. Using the social and human rights models of disability, the African Disability Protocol therefore takes stock of the unique African context while maintaining the gains and victories won in the Convention on the Rights of Persons with Disabilities.

Keywords

Human rights model of disability · African Disability Protocol · African context · Shifting approaches to disability in Africa

Introduction

In recent years, disability has received significantly greater attention in international human rights discourse. After decades of advocacy, disability rights activists have succeeded in shifting the conversation about disability from the medical and welfare fields to the human rights arena. At the global level, the idea of disability as a human rights issue is neatly encapsulated in the Convention on the Rights of Persons with Disabilities (CRPD), which was adopted by the UN General Assembly in 2006 and came into force on 3 May 2008. Africa embraced the CRPD as exemplified by its ratification by the majority of African states. At the time of writing, 50 of the 55 African states had ratified the CRPD. Indeed, the social and human rights approach to disability in the CRPD held enormous potential for the realization of human rights and fundamental freedoms by persons with disabilities which the medical and welfare models of disability had failed to do.

However, in spite of its progressive approach and extensive rights, the CRPD is yet to fully transform the rights experience of persons with disabilities in Africa. This is partly because the experience of disability discrimination faced by persons with disabilities in Africa is unique and distinct from the rest of the world. Similarly, the existing instruments in the African human rights system have not improved the enjoyment of human rights and fundamental freedoms by persons with disabilities in Africa. The CRPD has been criticized for not sufficiently taking the African context into account while the regional instruments are criticized for not sufficiently taking disability into account (Kamga, 2013).

Dissatisfied with the failure of the existing human rights legal framework at global and regional levels to achieve full inclusion for persons with disabilities in Africa, disability rights activists on the continent called for the adoption of an Africa-specific and disability-specific human rights instrument (Biegon, 2011). In 2018, the African Union subsequently adopted the Protocol to the African Charter on Human and People's Rights on the Rights of Persons with Disabilities in Africa (African Disability Protocol). This chapter demonstrates how the African Disability Protocol responds to the unique experience of disability discrimination faced by persons with disabilities in Africa by simultaneously curing the context deficiency at global level and deficient approach to disability at the regional level.

The chapter is divided into five sections. It begins, in the first section, by explaining why the social and human rights models of disability are capable of realizing the rights of persons with disabilities and why the medical and welfare models are not. The second section demonstrates the deficient approach to disability in African human rights instruments. In the third section, the lack of context-specific approaches in the CRPD are highlighted. The fourth section illustrates how the African Disability Protocol cures both deficiencies. The fifth and final section concludes the chapter by summarizing the main arguments.

Unearthing Deficiencies and Strengths in the Various Approaches to Disability

Over time, disability has been understood differently, as exemplified in the various approaches depicted in different models of disability (Retief & Rantoa, 2018). These models explicate the causes of disability and influence the response to disability both in societal attitudes and through law and policy. Indeed, the adequacy of the response to disability is determined, in part, by the specific approach to disability that is relied on.

The medical model of disability, which came about as a result of advances in science that led to a better understanding of impairments in the mid-1800s, perceives disability as inherent in the individual with impairment (Retief & Rantoa, 2018). Under the medical model, persons with disabilities are defined by their impairments or medical conditions (Aschalew, 2020). Because disability is viewed as a health issue, intervention occurs through medical means including medication and rehabilitation, which seek to "fix" the individual with impairment, rather than the environment (Olkin, 1999).

Closely related to the medical model is the welfare or charity model of disability. The charity model of disability regards disability as a welfare issue and is driven largely by emotive appeals to charity (Amponsah-Bediako, 2013). Under the welfare or charity model of disability, welfare associations must provide "care" for persons with disabilities (Grobbelaar-du Plessis & Reenen, 2011). Consequently, persons with disabilities are viewed "as objects of charity. and social protection" (Jere, 2011).

In the 1960s, the social model gradually replaced the medical and welfare models of disability. In stark contrast with the medical model, the social model distinguishes "impairment" from "disability." It perceives disability as a socially created disadvantage arising from an environment that takes little or no account of people with impairments (Union of the Physically Impaired against Segregation, 1976). Having the impairment alone does not result in disability. Rather, disability is perceived as the product of the "interaction between a person with impairment and attitudinal and environmental barriers" (CRPD, preamble para e). In contrast with the medical model, which treats the individual's impairment as the loci of the problem and responds by attempting to cure or rehabilitate the individual, the appropriate response under the social model involves making adjustments to the external environment in response to the person's needs.

In recent years, the human rights model of disability was introduced. This model affirms that all persons with disabilities are entitled to certain inalienable rights by virtue of their humanity (Amponsah-Bediako, 2013). The human rights model perceives persons with disabilities as holders of rights in line with the Universal Declaration of Human Rights (UDHR), 1948, which declares that "all human beings are born free and equal in dignity and rights" (article 1). It therefore shifts the emphasis away from the impairment and focuses on the entitlement of persons with disabilities to hold and exercise rights (Degener, 2016). The appropriate response to disability exclusion under the human rights model involves the promotion of the rights of persons with disabilities (Degener, 2016).

The manner in which disability is understood therefore influences the responses and interventions in law and policy. It is also an important factor in determining the level of inclusion of persons with disabilities. Because the medical model views disability as a medical condition inherent in the individual, it fails to take into account the impact of environmental and attitudinal barriers on the exclusion of persons with disabilities. Therefore, responses formulated in line with the medical model focus on curing and rehabilitating the individual as far as possible and do not involve interventions to address barriers in the external environment. Consequently, the medical model is conceptually incapable of fully and effectively including persons with disabilities in society.

Similarly, the welfare/charity model focuses on providing "care" to persons with disabilities and fails to address the impact of environmental and attitudinal barriers on the exclusion of persons with disabilities. Moreover, this model does not view persons with disabilities as subjects capable of holding rights, but as objects of pity and charity. Consequently, it is incapable of achieving the much needed empowerment of persons with disabilities through upholding their fundamental rights and freedoms.

In contrast, the social model of disability takes into account the impact of the individual impairment as well as the impact of environmental and attitudinal barriers. Recognizing that the disabling process "results from the interaction between persons with impairments and attitudinal and environmental barriers," the social model is cognizant of matters that the preceding medical and welfare models of disability are not (CRPD, preamble para e). The social model is therefore capable of adequately addressing the barriers to the full inclusion of persons with disabilities.

Similarly, the human rights model places emphasis on the identity of persons with disabilities as subjects of rights rather than objects of charity recognizing the right of persons with disabilities to hold and exercise all human rights and fundamental freedoms on an equal basis with others. Therefore, responses fashioned in line with the human rights model of disability address the deficiencies in the earlier medical and welfare models of disability. For that reason, the human rights model of disability holds great promise for the realization of the rights and fundamental freedoms of persons with disabilities in Africa.

In combination, the social and human rights models of disability complement each other in such a way that they have enormous potential to formulate responses that are capable of bringing about the required social change in the lives of persons with disabilities. Accordingly, this chapter subscribes to both the social and human rights models of disability as the approaches most capable of achieving full inclusion of persons with disabilities.

A Deficient Approach to Disability in the African Human Rights System Prior to the African Disability Protocol

In many African cultures, disability has historically been associated with disease, sin, and shame (Patterson et al., 2019). In Zimbabwe, for example, having a child with a disability is perceived by some as a sign of witchcraft or as evidence that the mother was promiscuous during her pregnancy (Chimedza & Peters, 1999). In Eswatini (formerly Swaziland), persons with disabilities are prohibited from participating in some national events because of the belief that if the king or queen mother encounters persons with disabilities, this will bring them bad luck (Kotze, 2010). These harmful beliefs have informed and influenced the dominant approach to disability found in the legislative, policy, and institutional frameworks in the African human rights system. The deficient approach to disability is exhibited in the reliance on the outdated medical and welfare models of disability as well as the inadequate coverage of disability in various African human rights instruments.

Prior to the adoption of the African Disability Protocol, the rights of persons with disabilities in Africa were scattered in various general and group-specific human rights instruments within the African human rights system. The provisions relating to disability in each of these instruments adopt the outdated and deficient medical and welfare approaches to disability, as evidenced by their reliance on the provision of "care," "protection" (welfare approach), "treatment," and "rehabilitation," (medical model approach) of persons with disabilities. The instruments also focus on the "needs" of persons with disabilities and require member states to provide "special measures" in response to those needs indicating a reliance on the medical and welfare approaches to disability as shown below.

The African Charter on Human and People's Rights (African Charter), which is the main human rights instrument in Africa, states that persons with disabilities are entitled to "*special measures* of protection in keeping with their *physical or moral needs*" (art 18(4) emphasis added). Abbay argues that the term "physical and moral needs" signifies measures whose purpose is to rehabilitate persons with disabilities rather than ensuring the enjoyment of their rights in all spheres of life (Abbay, 2015). This is evident in how states have responded to persons with mental disabilities. They have resorted to building mental asylums, such as Chainama Hospital in Zambia, for internment of persons with mental disabilities as a way of ensuring their "physical and moral needs," signifying a reliance on the medical model of disability.

Similarly, article 13 (1) of the African Charter on the Rights and Welfare of the Child (African Children's Charter) makes provision for "measures of protection" for children with disabilities in the following terms: "[e]very child who is mentally or physically disabled shall have the right to special measures of protection in keeping with his physical and moral needs.” Moreover, article 13 (2) of the African Children’s Charter requires member states to give *assistance* to “a disabled child and to those responsible for his care” and stipulates that such assistance “is appropriate to the child’s condition” indicating a medical and welfare approach to disability.

Crucially, article 13 of the African Children’s Charter deals with the rights of children with disabilities under the heading “[h]andicapped children.” “Handicapped” is an archaic term used to refer to persons with disabilities. The Oxford English Dictionary (1986) defines “handicap” as persons, especially children, who are physically or mentally defective. The term is believed to have originated with King Henry VII in his attempt to improve the welfare of disabled veterans following a brutal war in England in 1504. The King passed a landmark legislation proclaiming that begging in the streets is legal for persons with disabilities. This legislation allowed disabled veterans to go into the streets, with their “cap in hand,” to beg for money, thus the term “handicap” (Karapita, 2017). Labels are important because they affect how persons with disabilities are perceived (Galvin, 2003). Certain labels such as “handicapped” infer vulnerability and lack of agency. They position persons with disabilities as a separate group that is distinct from others in all material respects and is regarded in a negative light by society (Muzata, 2019). The use of the term “handicapped” also signifies a reliance on the deficient medical and welfare models of disability.

The Protocol to the African Charter on Human and People’s Rights on the Rights of Women in Africa (Maputo Protocol) contains provisions relating to women with disabilities. Article 23 of the Maputo Protocol emphasizes the “protection” as well as the “needs” of women with disabilities. Article 23 (a) of the Maputo Protocol provides that States parties undertake to “[e]nsure the *protection* of women with disabilities and take specific measures commensurate with their *physical, economic and social needs* to facilitate their access to employment, professional and vocational training, as well as their participation of decision-making” (Emphasis added). Similarly, section 23 (b) of the Maputo Protocol continues to highlight the need for “protection” of women with disabilities by stipulating that States parties should “[e]nsure the right of women with disabilities to freedom from violence, including sexual abuse, discrimination based on disability and the right to be treated with dignity.” Although the Maputo Protocol has achieved great strides in promoting the rights of African women in general, the rights of women with disabilities have lagged behind. This is largely because the Maputo Protocol focuses on the “care” and “protection” of women with disabilities instead of considering them as subjects capable of holding and exercising rights on an equal basis with others.

The African Youth Charter also exhibits a medical and welfare approach to disability. Article 24 (1) of the African Youth Charter provides that “[s]tates Parties recognise the right of mentally and physically challenged youth to *special care*.” The phrase “special care” indicates an approach to disability as a medical and welfare issue with persons with disabilities being perceived as recipients of “care” rather than as holders of human rights. Furthermore, the African Youth Charter uses language that emphasizes the individual impairment, rather than societal barriers, by referring to youth with disabilities as “physically and mentally challenged youth.”

The emphasis on impairment has been criticized for being derogatory thus reinforcing stigmatization (Viljoen & Biegon, 2014).

The provisions relating to disability in the African Union Convention for the Protection and Assistance of Internally Displaced Persons in Africa (Kampala Convention) are also based on the medical model of disability. Article 9 (2) (c) stipulates that States Parties shall "provide *special protection* for and *assistance* to internally displaced persons with special needs, including ... persons with disabilities..." (emphasis added).

Further evidence of the lack of a human rights approach to disability lies in the fact that the African human rights system has been underused in advancing disability rights (Heyns, 2001). This is evident when one considers the fact that there is only one communication involving disability that has been brought before the African Commission on Human and People's Rights (*Purohit and Moore v The Gambia*, 2003). In part, this is due to the perception of persons with disabilities as objects of charity rather than subjects entitled to human rights. In *Purohit and Moore v The Gambia,* the complainants argued that the provisions of the Mental Health Law in the Gambia, known as the Lunatics Detention Act, constitute a violation of the right to dignity of the person and the right to health (*Purohit* paragraph 1). The African Commission adopted a human rights approach and affirmed persons with disabilities' right to health as:

> vital to all aspects of a person's life and well-being, and is crucial to the realisation of all the other fundamental human rights and ... includes the right to health facilities, access to goods and services to be guaranteed to all without discrimination of any kind. (*Purohit* para 80)

The African Commission added that there should be no discrimination in accessing the right to health and encouraged the Gambia to:

> take concrete and targeted steps, while taking full advantage of its available resources, to ensure that the right to health is fully realised in all its aspects without discrimination of any kind. (*Purohit* paragraph 84)

The Commission also acknowledged the scarcity of resources in most African states but emphasized that the little resources at their disposal should be allocated in a nondiscriminatory manner.

The Commission further acknowledged that the labeling of persons with mental disabilities as "lunatics" and "idiots" is based on the medical model of disability and deprives them of their dignity (*Purohit* paragraph 59 and 60). *Purohit* is an important communication for persons with disabilities in Africa. It analyzed the situation of persons with mental disabilities from a human rights perspective. This rights-based approach affirms that persons with mental disabilities have a right to equal protection of the law and nondiscrimination. Abbay (2015) has argued that *Purohit* is important because it provided the African Commission with an opportunity to interpret and apply the provisions of the African Charter relating to persons with disabilities. It also provides a precedent for persons with disabilities to rely on in the future. The

Commission is to be commended for infusing a human rights approach to disability in Africa. However, the fact that the Commission has only ever received one communication relating to the rights of persons with disabilities continues to hint that persons with disabilities in Africa are not generally perceived as subjects of rights.

The African human rights instruments do not adequately address matters of disability. Various instruments do not expressly include disability in their nondiscrimination clauses. For instance, the African Charter fails to expressly include persons with disabilities in article 2, which sets out the grounds upon which discrimination is prohibited. Article 2 lists various grounds such as "race, ethnic group, colour, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status." Disability is not included in this list. It is implicitly rather than expressly included in the antidiscrimination clause in the African Charter through phrases such as "other status" (Abbay, 2015). Indeed, it is accepted that phrases including "such as" serve to introduce the various grounds upon which discrimination is prohibited and the phrase "other status" suggests that the list is not exhaustive (Biegon, 2011). Moreover, the phrases "every individual," "every human being," "every citizen," and "all people" signify that persons with disabilities are equally entitled to the rights and freedoms enshrined in the African Charter. In *Purohit,* the African Commission confirmed this when they held that disability is included in "other status" under article 2 of the African Charter.

Similarly, the provision on nondiscrimination found in article 3 of the African Charter on the Rights and Welfare of the Child (African Children's Charter) does not expressly include disability in its nondiscrimination clause. Children with disabilities are included within the ambit of this provision only through inclusive interpretation. Kamga correctly argues that "this approach fails to ensure the visibility of the rights of children with disabilities" (2013).

Furthermore, the provision on nondiscrimination in the African Youth Charter does not expressly include disability in the list of grounds upon which discrimination is prohibited, making it necessary to include disability through inclusive interpretation. The grounds listed in article 2 (1) of the African Youth Charter include race, ethnic group, color, sex, language, religion, political or other opinion, national and social origin, fortune, birth, or other status. Article 15 (4) of the African Youth Charter provides for nondiscrimination only with regard to one particular right, the right to employment. It affirms that states should "ensure equal access to employment and equal pay for equal work or equal value of work" and offers "protection against discrimination regardless of ethnicity, race, gender, disability, religion, and political, social, cultural or economic background."

The failure to expressly include disability in the discrimination clauses in the African Charter, the African Children's Charter, and the African Youth Charter (save for the provision relating to employment) can be remedied through inclusive interpretation. Nevertheless, this is undesirable as it leaves the matter open to different interpretations (Abbay, 2015). The recognition of the right of persons with disabilities to equality and nondiscrimination should not depend on inclusive interpretation, particularly when this right is explicitly protected in relation to other population subgroups (Abbay, 2015). Consequently, the equal application of the rights and freedoms of persons with disabilities remains weak and insufficient.

The inadequate handling of disability in some of the African human rights instruments is exhibited in the fact that not all types of disabilities are taken into account. For instance, article 13 of the African Children's Charter has been criticized for reducing disability to mental and physical impairments only (Kamga, 2013). Article 13 applies to "[e]very child who is mentally or physically disabled." This leaves out others, including children with visual impairments, and those with hearing and speech impairments. A similar approach is adopted in the African Youth Charter, which limits disability to mental and physical disability to the exclusion of other types of disabilities. Article 24 (1) of the African Youth Charter states that "States Parties recognise the right of mentally and physically challenged youth to special care and shall ensure that they have equal and effective access to education, training, health care services, employment, sport, physical education, and cultural and recreational activities."

Moreover, some of the instruments privilege certain rights over others in relation to persons with disabilities. The Maputo Protocol, for example, specifically mentions that women with disabilities have the right to access "employment, professional and vocational training as well as . . . participation in decision-making" (article 23 (b)). Other rights, particularly civil, political, and cultural rights, are not specifically mentioned (Abbay, 2015). Similarly, the African Youth Charter specifically limits the provision of "special care" to specific rights including "education, training, healthcare services, employment, sport, physical education, and cultural and recreational activities" (article 24 (1)).

As shown above, the African human rights instruments are largely modeled on the medical and welfare approaches to disability. The African human rights system considers persons with disabilities as objects of charity and welfare rather than as subjects with rights (Ngwena, 2006). The use of terminology and phrases such as "handicapped," "special care," and "physical and moral needs," among others, indicates a focus on individual impairment without taking account of environmental and social factors (Oyaro, 2015). Consequently, these instruments fall short of international human rights standards such as those prescribed in the CRPD.

Contextual Gap in the CRPD

At the global level, the CRPD adopts a more holistic approach to disability than the African human rights system. The CRPD espouses both the social and the human rights models of disability. In accordance with the social model, the CRPD recognizes that disability "results from the interaction between" an individual with impairment and various barriers (CRPD, preamble para e). Barriers may be social, cultural, material, physical, or attitudinal, and they exclude persons with impairments from mainstream life (Franklin et al., 2018). In line with the human rights model of disability, the purpose of the CRPD is to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (CRPD art 1). The CRPD therefore contains an extensive list of human rights and fundamental freedoms to which persons with disabilities are entitled. Articles 10–30 of the CRPD cover civil, political, economic, social, and cultural rights. The right to equal recognition before the law entrenched in article 12 of the CRPD is particularly significant to the human rights approach to disability. Article 12 (2) provides that "[s]tates Parties shall recognise that persons with disabilities enjoy *legal capacity* on an equal basis with others in all aspects of life" (emphasis added). The meaning of the term "legal capacity" was the subject of much contention during the drafting of the CRPD (Dhanda). There was contention about whether legal capacity includes capacity to hold rights as well as the capacity to act in order to exercise those rights. In the interest of progress, a compromise was reached and the CRPD did not define the term "legal capacity" anywhere in its text. Nevertheless, the Committee on the Rights of Persons with Disabilities clarified that legal capacity means both the capacity to hold rights and the capacity to act (General Comment number 1). The CRPD acknowledges that persons with severe disabilities may require support and provides that States Parties have a duty to provide this support. According to article 12 (3), States Parties "shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity." Contrary to the dominant substituted decision-making regime, requiring support in order to make decisions and act to exercise one's rights is no longer a justification for the denial of legal capacity. Rather, the provision of support is regarded as a vital part of the right to legal capacity. The CRPD is therefore much more than just an instrument that lists the rights and fundamental freedoms to which persons with disabilities are entitled. Through its provisions on legal capacity and supported decision-making, the CRPD demonstrates an unwavering commitment to a human rights approach to disability according to which all persons with disabilities hold and exercise their human rights and fundamental freedoms on an equal basis with others. In that respect therefore, the CRPD adopts an approach that is capable of enabling persons with disabilities to hold and enjoy human rights and fundamental freedoms.

The CRPD was well received by African countries. At the date of writing, 50 of the 55 African States had ratified the CRPD with Botswana being the latest country to ratify it on 12 July 2021. Moreover, a number of African states participated in the drafting process of the CRPD. Nevertheless, some African disability activists and scholars have argued that while the CRPD is undoubtedly relevant in Africa, it does not adequately represent the African context and experience (Appiagyei-Atua, 2017). Some of the concerns are that the CRPD does not provide for harmful traditional beliefs and practices that are rampant in Africa and have driven the mutilations and ritual killings of persons with albinism. Matters of HIV/AIDS as well as poverty that have a significant impact on the enjoyment of human rights and fundamental freedoms by persons with disabilities are also not addressed in the CRPD (Kamga, 2013). Although the CRPD falls short of explicitly protecting persons with disabilities infected with HIV/AIDS, persons with disabilities are entitled to access HIV/AIDS health programs on an equal basis with others under article 25 (Human Rights Watch, 2014).

Dissatisfied with the manner in which the African human rights system addressed disability rights and the lack of local context in the CRPD, disability activists in Africa began to call for the adoption of an Africa-specific and disability-specific instrument.

Addressing Gaps at the Global and Regional Levels: The African Disability Protocol and Other Relevant Regional Documents

In order for Africans with disabilities to realize their rights and fundamental freedoms, there was a need to adopt a new approach that is simultaneously relevant to the unique African context, capable of promoting the equal enjoyment of all human rights and fundamental freedoms by persons with disabilities in Africa. This came in the form of the Protocol to the African Charter on Human and People's Rights on the Rights of Persons with Disabilities in Africa (African Disability Protocol).

Prior to the adoption of the African Disability Protocol, there was already a shift taking place from the medical and welfare models to the social and human rights models of disability. The initial impetus for Africa's transition from the medical to the social model of disability began in 1980 with the Africa Regional Conference on the International Year of the Disabled which resulted in the adoption of the Agreement for the Establishment of the African Rehabilitation Institute (the ARI Agreement). Prior to the establishment of the ARI, Member States of the Organisation of African Unity (OAU, established in 1963), the precursor to the African Union, addressed the needs of persons with disabilities at domestic level. The African Rehabilitation Institute (ARI) was subsequently established in May 1988, in Harare, Zimbabwe. ARI was responsible for developing subregional and regional training and research programs on the rehabilitation of persons with disabilities. The ARI Agreement is based on the medical and welfare model of disability as shown in article 3 which states that one of the mandates of the ARI is to assist member states to "enhance disability prevention and rehabilitation services and to ensure the inclusion of persons with disabilities in all aspects of life." The core functions of the ARI center exclusively around the provision of rehabilitation services, indicating a reliance on the medical and welfare approaches to disability. Some of the core functions include the formulation of a "unified approach for promoting the development of prevention and rehabilitation services" (a); the creation of "facilities to satisfy the needs of handicapped Africans who, because of their disability, find it difficult to adapt themselves to the rapidly changing world" (b); the promotion of the development of "rehabilitation centres in all countries of the African continent . . ." (c); and the creation of "favourable conditions for inter-African co-operation and mutual assistance as part of rehabilitation and strengthening the already existing rehabilitation institutions in various parts of Africa. . ." (d). The use of phrases such as "handicapped Africans" and "creation of facilities to care for" persons with disabilities indicates a reliance on the medical and charity models of disability (Biegon, 2011).

The shift toward a human rights approach commenced during the OAU's Ministerial Conference on Human Rights in 1999. This Ministerial Conference resulted in the adoption of the Grand Bay (Mauritius) Declaration and Plan of Action, which dealt with the rights of persons with disabilities, people living with HIV/AIDS, women, and children. As Murray correctly points out, this document "indicated a shift from human rights being seen as the domain of the African Commission in Banjul to a more integrated perspective within the OAU itself, and marked an important turning point in the OAU's recognition of its role in this regard" (Murray, 2004). After the OAU Ministerial Conference, the OAU Labour and Social Affairs Commission (LSAC) declared 1999–2009 the African Decade of Persons with Disabilities. The aim of the African Decade was to drive the implementation of the World Programme of Action Concerning Disabled Persons (WPA) in Africa.

During the African Decade of Persons with Disabilities, the OAU was transformed to AU through the AU Constitutive Act. The AU Constitutive Act clearly defined the human rights mandate of the AU (Baimu, 2001). It provides that one of the AU's objectives is to "promote and protect human and peoples' rights in accordance with the African Charter on Human and Peoples' Rights and other relevant human rights instruments" (AU Constitutive Act, article 3(h)). As a result of the AU's objective to safeguard human rights the Continental Plan of Action for the African Decade of People with Disabilities of 2002 (CPOA) was adopted. This instrument was based on the human rights model of disability and focused on strengthening equality, empowerment, and full participation of persons with disabilities (Biegon, 2011). After the CPOA, in May, 2003, AU Ministerial Conference on Human Rights in Africa was held in Kigali, Rwanda, followed by the Disability African Regional Consultative Conference in Johannesburg, South Africa. The Rwanda Ministerial Conference encouraged African states to support ARI. It also adopted the Kigali Declaration. The aim of the Kigali Declaration was "to develop a Protocol on the protection of the rights of people with disabilities and the elderly" (Kigali Declaration, paragraph 20).

Following the Johannesburg Conference, the Secretariat of the African Decade of Persons with Disabilities (SADPD) was established to coordinate and ensure that governments, organizations of persons with disabilities (OPDs), and other non-governmental organizations (NGOs) implement the CPOA. The SADPD facilitated five programs in poverty reduction, gender law and policy, livelihood opportunities, and youth and children, in various countries including Ethiopia, Kenya, Rwanda, and Senegal. National African Decade Steering Committees were also created in Burkina Faso, Burundi, Cameroon, Cape Verde, Egypt, Gambia, Ghana, Guinea, Mali, Mauritania, Namibia, Senegal, South Africa, Tanzania, Togo, and Zambia (Kamga, 2013).

The next regional disability rights initiative occurred in 2007, which was the Africa Campaign on Disability and HIV/AIDS. It was also based on the human rights model of disability. This campaign brought together disabled persons and AIDS organizations with the aim of incorporating a disability rights lens within policies and programs on HIV in Africa. Thereafter, the 2008 Kampala Declaration on HIV was developed and signed for that very purpose (Gerntholtz et al., 2010).

The years 2010–2019 were subsequently declared as the second African Decade on the Rights of Disabled Persons.

The last social and human rights-based initiative occurred in 2008 through the Windhoek Declaration on Social Development (Windhoek Declaration) (2008). Among the affirmations and resolutions related to persons with disabilities in the Windhoek Declaration was a commitment by states to promote human rights and improve the quality and standard of living of their citizens, including persons with disabilities (Windhoek Declaration, preamble). The Windhoek Declaration took note of the challenges that persons with disabilities face in Africa, such as poverty, violence, and lack of access to social services, among others. In order to combat these challenges, the Windhoek Declaration envisaged the adoption of a social development program under the auspices of the AU Commission that would combat poverty, and promote employment, human rights, dignity, and access to social services by marginalized groups including persons with disabilities. Although these are positive features, Abbay (2015) argues that the "social development" focus of the Windhoek Declaration reinforces disability as a social development rather than a human rights issue.

Although the African Decade of Persons with Disabilities was predominantly founded on a social welfare perspective, it had a human rights tinge. It was based on the principles of full participation, equality, and empowerment of persons with disabilities, which African states were encouraged to foster. The gains of the African Decade of disabled persons can be seen in South Africa, which developed a rights-based legislative framework and incorporated the principle of self-representation of persons with disabilities.

The African Union subsequently adopted the African Disability Protocol on 29 January 2018. The Protocol was adopted in accordance with article 66 of the African Charter on Human and People's Rights (Banjul Charter) which states that "[s]pecial protocols or agreements may, if necessary, supplement the provisions of the present Charter." The African Disability Protocol is not yet in force since it has not yet received the requisite number of ratifications. Fifteen member states need to ratify the African Disability Protocol in order for it to come into force (Article 38 (1) African Disability Protocol). At the date of writing, the African Disability Protocol was signed by 11 out of 55 African countries. These countries are Angola, Burkina Faso, Cameroon, Central African Republic, Gabon, Mali, Malawi, Mozambique, Rwanda, South Africa, and Togo. Only three countries have ratified the African Disability Protocol, namely, Kenya, Mali, and Rwanda. Despite the fact that the African Disability Protocol is not yet in force, it remains an integral part of the African human rights architecture, and it is only a matter of time until it comes into force. The African Disability Protocol addresses gaps in the approach to disability found in the African human rights system by abandoning the medical and welfare approaches and employing the social and human rights models of disability.

The Convention on the Rights of Persons with Disabilities (CRPD) has had a significant influence on the African Disability Protocol. The content of the African Disability Protocol is testament to the influence of the CRPD. Like the CRPD, the

African Disability Protocol adopts a social and human rights approach to disability. In article 1 of the African Disability Protocol, the term "persons with disabilities" includes those with "physical, mental, psychosocial, intellectual, neurological, developmental or other sensory *impairments which in interaction with environmental, attitudinal, or other barriers* hinder their full and effective participation in society on an equal basis with others" (emphasis added). Furthermore, the African Disability Protocol adopts a human rights approach to disability. The African Disability Protocol reaffirms the rights that are found in the CRPD. The following rights are found in both the CRPD and the African Disability Protocol: the right to equality and nondiscrimination (Art 5 and 6 African Disability Protocol and article 5 CRPD); the right to equal recognition before the law (Art 7 African Disability Protocol and article 12 CRPD); the right to life (Art 8 African Disability Protocol and art 10 CRPD); liberty and security of person (Art 9 African Disability Protocol and art 14 CRPD); freedom from torture or cruel, inhuman, and degrading treatment or punishment (Art 10 African Disability Protocol and art 15 CRPD); situations of risk (Art 12 African Disability Protocol and art 11 CRPD); access to justice (Art 13 African Disability Protocol and art 13 CRPD); right to live in the community (Art 14 African Disability Protocol and art 19 CRPD); accessibility (Art 15 African Disability Protocol and art 9 CRPD); education (Art 16 African Disability Protocol and art 24 CRPD); health (Art 17 African Disability Protocol and art 25 CRPD); habilitation and rehabilitation (Art 18 African Disability Protocol and art 26 CRPD); work (Art 19 African Disability Protocol and art 27 CRPD); adequate standard of living (Art 20 African Disability Protocol and art 28 CRPD); participation in public and political life (Art 21 African Disability Protocol and art 29 CRPD); freedom of expression and opinion (Art 23 African Disability Protocol and art 21 CRPD); access to information (Art 24 African Disability Protocol and art 21 CRPD); participation in sports, recreation, and culture (Art 25 African Disability Protocol and art 30 CRPD); family (Art 26 African Disability Protocol and art 23 CRPD); women and girls with disabilities (Art 27 African Disability Protocol and art 6 CRPD); and children with disabilities (Art 28 African Disability Protocol and art 7 CRPD).

Crucially, the African Disability Protocol includes a definition for legal capacity that is in line with that found in the Committee on the Rights of Persons with Disabilities' general comment number 1. Article 1 of the African Disability Protocol defines the term "legal capacity" as the "ability to hold rights and duties and to exercise those rights and duties." Neither the CRPD nor the African Disability Protocol creates new rights. Instead, they formulate existing rights in a manner that is specific to the experience of persons with disabilities. Because of its reliance on the social and human rights models of disability, the African Disability Protocol is capable of transforming the rights experience of persons with disabilities in Africa.

The African Disability Protocol also addresses the contextual gap in the CRPD by including rights that are specific to the African context. It includes issues and rights that are specific to the African context like ritual killings (article 1), harmful practices (article 11(1)), youth with disabilities (article 29), older persons with disabilities (article 30), persons with disabilities as duty bearers (article 31), definition of deaf culture (article 1), and the role of the family, caregivers, and community (article 25) and also includes marginalized groups such as persons with albinism.

The African Disability Protocol has also reformulated and extended CRPD rights in order to suit the African context. The African Disability Protocol has restated the rights of access to justice, living in the community, legal capacity, habilitation and rehabilitation, freedom from torture, work and employment, and political and public participation. These rights have been contextualized to suit the African context in different ways. Access to justice has been extended to include customary law forms of justice (article 13(2)). Living in the community includes living independently in the community (article 14). Legal capacity includes the right to hold documents of identity (article 7 (2)(f)). The right to habilitation and rehabilitation includes the requirement to develop, adopt, and implement standards that are suited to local conditions (article 18 (e)). Freedom from torture includes the inclusion of forced sterilization and other invasive procedures (article 10). Work and employment includes "reserving and enforcing minimum job quotas for employees with disabilities" in the public sector, and the principle of equal pay for equal work (article 19). Political and public participation includes amending laws that restrict the right to vote, stand for, or remain in office (article 21).

On certain issues, the African Disability Protocol is not as detailed as the CRPD. Article 15, on accessibility, omits references to private entities, training, and the Internet. Article 16, on education, does not mention braille, alternative script, augmentative and alternative means, modes and formats of communication, orientation and mobility, peer support and mentoring, and raising disability awareness of staff across all levels of education. Article 18, on habilitation and rehabilitation, omits reference to earliest possible stage, multidisciplinary team, and the concept of being voluntary. Article 19, on work and employment, omits reference to the open labor market. Article 20, on the right to an adequate standard of living, omits access to public housing programs, and women and girls as a specific group requiring inclusion in social protection programs. Article 25 on family is not explicit about the duty states have to assist persons with disabilities in raising children.

Despite these areas of concern, the African Disability Protocol is dedicated to promoting and protecting the rights of persons with disabilities in Africa. Article 36 stipulates that "[n]o provision in this Protocol shall be interpreted as derogating from the principles and values contained in other relevant instruments for the realization of the rights of Persons with Disabilities in Africa." It further provides that "[i]n the event of a contradiction between two or more provisions of this Protocol, the interpretation which favours the rights of Persons with Disabilities and protects their legitimate interests shall prevail" (article 36 (2)). A similar safeguard clause is found in article 4 (4) of the CRPD. Therefore, the African Disability Protocol addresses the deficient approach to disability in the preexisting African human rights instruments as well as the lack of local context in the CRPD.

Conclusion

Cumulatively, the social and human rights models of disability hold great promise for the adequate protection of the rights of persons with disabilities and their full inclusion in society. In contrast with the medical and welfare approaches to disability, the social model takes into account the impact of external environmental barriers, while the human rights model perceives persons with disabilities as subjects capable of holding and exercising human rights. Prior to the adoption of the African Disability Protocol, the African human rights instruments adopted the deficient medical and welfare approaches to disability. Furthermore, the few provisions expressly addressing disability did so in an inadequate manner. At the global level, the CRPD does not sufficiently depict the African context and experience with pertinent matters such as harmful practices and traditional systems of justice being absent from its text. The African Disability Protocol addresses both the deficient approach to disability in the African human rights system and the lack of local context in the CRPD. It therefore brings rights home while taking the African context into account.

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Part IV

Studying Critical Disability: A Consolidating Field

Studying Critical Disability: A Transformative and Inclusive Agenda for Social Change – Introduction

18

Theresa Lorenzo

Contents

Abstract

Disability studies has grown as an emerging discipline since the 1980s across mainstream disciplines in academic, which has influenced policy processes at global and local levels. The chapters of this section present both personal and political experiences of the authors who have engaged in critical dialogues in their profession, which has generated a credible shift in co-creating disability-inclusive curricula in higher education institutions involving persons with disabilities teaching and researching with academics, and students, some of whom have experienced barriers to equal opportunities due to their impairments themselves; the complexity of the social determinants of disability that have entrenched inequalities and discrimination experienced by persons with disabilities and their families, within their communities and wider society; and the stereotypical views of disability that are challenged by using intersectionality as a lens to explore the axes of privileges and power in their different academic disciplines, so that we dismantle systemic structures that cause inequalities in access to health, education, and economic development so there is sustained social change.

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Introduction

When asked to be an editor of this section, it raised critical questions in my mind as an occupational therapist about how we explore power and privilege related to disability inclusion for social change in the discipline of occupational therapy as a start and then beyond other disciplines in health sciences, humanities, law, business sciences, and economics. I also wondered, in light of the objectives for this section, how a social discipline could decolonize its epistemology and who sets the agenda of what is written by who. Reflecting on these questions highlighted the benefits of using an intersectionality lens to critique intradisciplinary theories and practices with the aim of strengthening disability-inclusive social systems. Interrogating the interconnected nature of social categorizations from a disciplinary perspective could reveal transformative and more inclusive approaches to disrupting systems of discrimination or disadvantage, especially at local government level as the executive hub for the implementation of disability-inclusive policy and practice across all state sectors. Similarly intradisciplinary epistemic critique in the higher education sector would ensure that the graduates we produce are able to implement inclusive policies and practice.

I studied for a Bachelor of Science in Occupational Therapy at a South African university and qualified in the mid-1980s. The medical model of disability that focused on an individual's impairment formed the framework for the curriculum. There was very little reference to the socioeconomic and political determinants of human health and well-being, so we did not exit the program with professional competences for promoting social justice and inclusive social change. Reflecting on my professional socialization now, I am struck by the marked absence in the curriculum then to conscientize occupational therapy students toward social, economic, and political development that would prepare us for context-relevant practice. For example, we treated many young black youths who sustained upper limb amputations from throwing hand grenades during political protests in the townships. They were further disabled, since we were not allowed to issue upper limb prosthesis to them as these were considered "dangerous items" in prison. No one in the rehabilitation team thought to advocate for the prisoner's rights to optimal rehabilitation.

Two years after graduating, I was offered a research post in a rural "homeland" of South Africa that extended my grasp of the social and political injustices of apartheid. The destruction of family and economic systems caused by the migrant labor system was seen all around the rural villages where I worked. When the research ended, I was able to get a therapy post in the hospital. I struggled to know how to respond to poverty and to be involved with persons with disabilities to address their needs in a relevant and meaningful way. With little understanding of sociology and the politics of poverty and development, I experienced inner conflict between the conventional understanding of my professional role and the absence of discipline-specific knowledge and skills in addressing the social determinants of disability. My Christian faith and spirituality became a source of strength, hope, and inspiration to make sense of the professional impasse I found myself in. The growth of deep, meaningful cross-cultural friendships with a diverse range of people whose beliefs were different to my own gently challenged me to reflect on my beliefs and values. There were three women (Bahai, Jewish, and Christian), in particular, who as mentors had an impact on my transformation in political conscientization including a deeper understanding of the politics of disability and the intersections with race, disability, gender, religion, and class. They each brought a different perspective to life and enriched my appreciation of the diversity of faiths that enriched community living and working.

Those formative years shifted my practice from an individual rehabilitative to a human rights and development approach. My emerging political conscientization was further fuelled by my interactions with Disabled People South Africa (DPSA), which led to me to understand disability as a form of social oppression. The Rural Action Group on Disability (RURACT) provided regional and national forums for discussion, debate, and social engagement between disabled people who were members of DPSA and service providers such as myself from the health, education, and welfare sectors. With exposure to disability activism, I began to see that the components of equal opportunities and social integration of community-based rehabilitation (CBR) (WHO, ILO, and UNESCO, 1994) could make a direct contribution to the human development of persons with disabilities. The rural communities where I worked provided an abundance of opportunities for development projects.

Although the shift in professional focus was overwhelming for a young practitioner, my approach to inclusive development was deeply influenced by Paulo's Freire's approach of conscientization through respect for everyone's experience and the idea that knowledge and action produced through mutual learning become the catalysts for social change (Hope & Timmel, 1995). My work in rural health and development also involved the training of undergraduate health science students from one of the universities in rural health and inclusive development. Final-year medical, occupational therapy and physiotherapy students did 3- and 4-week rural blocks at the hospital, respectively. Training students was an opportunity to hone my skills in interdisciplinary teaching and intersectoral practice, as well as in managing conflicts and tensions between academia and disability activism.

Together with the rehabilitation team at Tintswalo Hospital in Acornhoek, I took some bold professional steps in rural development practice through initiating CBR services, focused on training early childhood development centers to become disability inclusive and skills development for youth and adults with disability to start sustainable livelihoods projects. I became increasingly convinced that women have much to contribute to our understanding of disability in the context of poverty, Inclusive development, and the role of practitioners to facilitate inclusive services and systems for sustainable development. We applied Freire's principles of creating conscious awareness; finding relevance through identifying strong feelings; and problem-posing on the need for community re-integration for persons with disabilities, to plan a curriculum together with the Department of Occupational Therapy at the University of the Witwatersrand for training community rehabilitation workers (CRWs) as mid-level workers, using action reflection cycles.

My continued involvement with the disability rights movement during this time meant that I had to grapple with the "health and disability" debate (Lorenzo, 1991; Lorenzo, 2001a, b). I was fortunate to do a Masters in Community Disability Studies at the Centre for International Child Health at the University of London after 7 years of rural experience. Here I met disabled academics such as Mike Oliver and Vic Finkelstein who influenced my thinking regarding the contributions disabled people could make in academia. Afterward, I worked for a primary health-care NGO back in South Africa, before accepting a lecturing post at the University of Cape Town in 1996. Straddling the two worlds of academia and a nongovernment organization (NGO) practice provided the opportunity for me to meet and work with the Disabled Women's Development Programme of Disabled People South Africa (DPSA) while expanding the undergraduate occupational therapy curriculum to include competences in disability-inclusive community development. My experience as a facilitator in CRW training programs, as well as capacity building workshops for the Disabled Children's Action Group (DiCAG) and lecturing in CBR and Disability Studies, provided opportunities for me to reflect on how the occupational therapy profession needed to change.

I began to realize that change was a complex, intricate process that occurred on multiple levels and that the academy also needed to change to address the power dynamics in service delivery and partnership development (Lorenzo & Cloete, 2004). A growing interest in initiating a disability studies program in partnership with DPSA and DiCAG in South Africa started to emerge while they were guest lecturers in the Masters of Science in Occupational Therapy program at University of Cape Town. Together with members of DPSA and DiCAG and the Centre for Disability Studies at Leeds University in the UK, through a Higher Education Link Programme award from British Council, we developed a curriculum for a Postgraduate Diploma in Disability Studies, using recognition of prior learning as an assessment strategy for redressing exclusion from the education system for applicant without a first degree. Two of the authors of chapters in this section who accessed the program through RPL have obtained their PhDs. In this way, disability studies has raised critical consciousness in academia and the disability movement and wider civil society and government, in a way that has generated authentic, transformative, and inclusive social change.

The chapters in this section illustrate this golden thread of how practitioners and policy makers across all sectors of society, and academics across all disciplines, who engage in "studying critical disability" find a space to empower themselves to address the rights of persons with disabilities and their families, which leads to meaningful social change. The presence of the coronavirus (COVID-19) has shown up global inequalities and the urgent need for strategic transformative and inclusive development. At times of such disasters and emergencies, persons with disabilities are further marginalized and excluded (Ned et al., 2020; McKinney et al., 2021). They are also at higher risk of contracting the virus because of factors that include the need for interpersonal caregivers and living in residential facilities.

Studying critical disability is articulated as a form of knowledge co-production that is both collaborative and disruptive. Epistemic collaboration is valued as a strategy for the emergence of transdisciplinary theories and practices suited to meet the sustainable development needs of persons with disability in a globalizing world. Disruptive knowledge production is advocated as a strategy to foreground, critique, and challenge the hegemony of the many forms of oppression that individuals, families, and communities experience: the hegemony of global north; the hegemony of white privilege; the hegemony of professionals; the hegemony of patriarchy; and the hegemony of ableism, to name a few. The diverse positioning of the authors enriches the critical engagement with existing knowledge in critical disability studies. Ranging from academics, professionals, and non-professionals, who may also be persons with a disability, and practitioners on the ground, the authors provide a global north and south balance of perspectives on inclusive practices in all spheres of life.

Hisayo Katsui and Jennifer Muderedzi explore the structural violence of poverty and disability through a case study of families of children with cerebral palsy in rural Zimbabwe. They explain the convergences between critical disability studies and the disciplines of economics, political science, and international development by describing the vulnerability and embodied inequalities of these families. In so doing, they provide practical exemplars for the realization of the UN Agenda 2030. They argue that social disciplines too often take vulnerability and inequalities as ontological facts; they conclude that a critical disability perspective provides for a radical change in how these disciplines analyze and theorize structural violence.

Olwethu Sipuka and Sindile Ngubane-Mokiwa focus on higher education institutions and their leadership in addressing social justice. They argue that higher education institutions need to lead significant curricular change so that all academic disciplines prepare their graduates for disability-inclusive development. In particular, academic programs for the health, education, economics, and social development sectors should develop curricula that address the complexities of structural and systemic changes needed for inclusive social change, underpinned by political empowerment approaches.

Lieketseng Ned, Lucia Hess, Anthea Hansen, Sumaya Gabriel, and Amshuda Sonday apply a critical disability studies lens to the rehabilitation sciences curricula. They argue that the social determinants of disability are closely linked to the social determinants of health. Professional transgression and professional identity are co-created by an interdisciplinary focus in higher education institutions.

Christina Sadiki, Gubela Mji, Lucia Franco, and Lindsey Nicholls write on reciprocity in co-creation and co-production of knowledge through recognizing the need to hear the voices of mothers of children with disability traditional healers and elite of rural communities and persons with psychosocial disabilities who are marginalized and experience discrimination and isolation as a result of multiple hegemonies in healthy and higher education systems.

Disability Studies – Here today, gone tomorrow is a reflective critique of the roots of disability studies in the UK and USA by one of the leading disabled academics and activist in the UK, **Colin Barnes**, who was Professor of the Centre for Disability Studies at University of Leeds. He has written with **Simon Prideaux**.

The chapter makes a critical contribution regarding the socio-political dimensions of disability that are at risk of being lost in the current academic and policy debates, globally and nationally.

Closing Reflections

Studying critical disability presents opportunities for demystifying disability practice, professionalism, and research as vestiges of power and privileges that serve only to alienate and exclude certain people. Paulo Freire's pedagogy of the oppressed and his principles of adult education are still relevant today in considering the global shifts to disrupt ongoing oppression marginalization and isolation that exacerbate inequalities. If we are not conscious of the different forms of power, we may further oppress persons with disabilities through our policies, practice, and research. The writings of many disability activists and academics conscientized me about how persons with disabilities have been alienated and excluded from research and socioeconomic and political development, when researchers and practitioners remain unaware of the power of language and education.

I hope that practitioners, policy makers, academics, and researchers are encouraged to work in authentic partnerships with persons with disabilities at grassroots, national and regional levels, and, in so doing, embrace the transitions and differences that have potential to enrich everyone's lives. As Hartley (2002) commented that while knowledge is power, sharing knowledge is progress. I encourage practitioners, researchers, academics, and policy makers to engage with persons with disabilities to promote and sustain inclusive development. The critical turning points and lessons that are shared in the chapters in this section will hopefully shape the values and beliefs that inform an inclusive development approach so that equal opportunities for persons with disability move beyond being hidden aspirations to being fully achievable through reciprocal relationships of learning, being, belonging, doing, and becoming.

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Globalization and the Changing Face of Inclusive Development

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Hisayo Katsui and Jennifer Muderedzi

Contents

Abstract

This chapter explores the convergences between critical disability studies and the disciplines of economics, political science, and international development. We look ahead to UN Agenda 2030, theorizing the impact of globalization on disability inclusion and sustainable human development within an emerging new world order. We scrutinize the case of Tonga families with children with cerebral palsy in Zimbabwe, through which their vulnerability and embodied inequalities are shed light on so as to understand global and structural violence. We argue that vulnerability and inequalities are too often taken for granted as an ontological fact. We conclude that the critical disability perspective enables us to radically change our analysis by focusing on the starting point of vulnerability and inequalities.

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Introduction

This chapter describes the inequalities and vulnerability experienced by persons with disabilities and their families in the Global South using a case study of Tonga families with children with cerebral palsy in Zimbabwe. We use structural violence (Galtung, 1969) as a theoretical framework to examine the disintegrated disability in the global society and critically analyze the families' inequalities and vulnerability. Using a critical realist perspective of disability studies (see Vehmas & Watson, 2013), we answer the following three key questions: (1) How vulnerable are the Tonga families in the context of structural violence? (2) What are the embodied inequalities? (3) How can a critical disability perspective contribute to the sustainable development discourse in this time of globalization?

In the era of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) (2006) and the Sustainable Development Goals (SDGs) (2015), disability inclusion has become more important on the international political agenda than ever before. In line with the ideology of the disability-specific convention, the SDGs strive to leave no one behind, including persons with disabilities. The global discourse on disability seems to have changed dramatically since the time of UN Universal Declaration of Human Rights (1948). The declaration made only one single reference to disability in Article 25, whereas the SDGs have a standalone goal of inequality reduction and refer to disability and persons with disabilities in their various targets and indicators related to education, growth and employment, inequality, accessibility, data collection, and monitoring (Katsui, forthcoming). Today increasing efforts are being made to create disability inclusion guidelines and policies such as the United Nations Disability Inclusion Strategy (2019) and the UN Policy Brief on a Disability-Inclusive Response to COVID-19 (2020). In other words, the political will toward disability inclusion has strengthened at the global policy level.

However, a huge gap remains between the globalization of disability inclusion in sustainable development discourse and in local realities (Katsui & Chalklen, 2020). The COVID-19 pandemic has manifested this gap in reality. Under the pandemic circumstances, persons with disabilities around the globe have to fight to maintain their disability services, if they have any at all. Many of the services have been put on hold and consequently greatly jeopardize the well-being and health of these people (Abrams & Abbott, 2020; Langa, 2020). The total extent to which the pandemic has negatively impacted this specific group of people is not yet exactly known. Nevertheless, the aforementioned UN Policy Brief on a Disability-Inclusive Response to COVID-19 (2020) already displays extremely worrying realities:

> *'The global crisis of COVID-19 is deepening pre-existing inequalities, exposing the extent of exclusion and highlighting that work on disability inclusion is imperative. People with*

> *disabilities—one billion people— are one of the most excluded groups in our society and are the hardest hit in this crisis in terms of fatalities. (United Nations,* 2020*: 2*)

Nevertheless, the inequalities experienced by persons with disabilities are embodied and thus individualized (Katsui & Mesiäislehto, 2022). They often remain undiscovered if careful attention is not paid to their perspectives. In this context, structural violence provides a useful analytical framework. The concept of structural violence describes how economic, political, legal, and other social structures can prevent individuals, groups, and societies from reaching their full potential. It refers to systematic ways in which social structures harm or otherwise disadvantage individuals (Galtung, 1969). Structural violence is useful for understanding the real dynamics of inequalities and how power works (see Farmer, 2004). Global and local social fabrics are intertwined in the structure at stake and are embedded in political and economic organization at both local and global levels (ibid.), in their deep histories (Farmer, 2010:293), and in embodied experiences (Katsui & Mesiäislehto, 2022). This analytical framework of structural violence enables us to investigate structural power relations and inequalities.

Vulnerability is another key concept through which critical disability studies help us understand the disintegrated phenomenon of disability in local realities (see Heikkilä et al., 2020). Vulnerability as a concept is notoriously absent from the mainstream discussions on disability, probably due to the stigma that the notion is perceived to carry and the way in which it is seen to internalize and individualize disability as an ontological factor, which contributes to the normalization of the existing power relations within societies (Clough, 2017). The vulnerability of persons with disabilities has long been understood as a direct consequence of individual impairment in a medical model of disability (Barnes, 1991). The disability community extensively challenged this approach for individualizing disability and victimizing persons with disabilities, which stigmatizes them (e.g., Goodley, 2014; Grue, 2016). This change led to the emergence of a social model of disability, which contested the very assumption of "normality" and redefined disability as a form of social oppression (French, 1994). Consequently, contextual factors became a more important focus than impairments in deconstructing social vulnerabilities. The difference between inherent/ embodied and situational/embedded vulnerability became prominent. Furthermore, the UN CRPD, more precisely a human rights-based approach brings to the fore the notion of rights-holders and full subjects among persons with disabilities. A critical realist perspective in disability studies acknowledges particular vulnerability so that individuals can have their rights realized on an effectively equal basis with others, which is a precondition for the universality of social justice, not only in books but also in practice (Heikkilä et al., 2020).

At the intersection of the local and global fabrics of vulnerability and inequalities, this chapter first introduces the methodology of our case study in Binga, Zimbabwe. Second, we present profound experiences of vulnerability and inequalities and analyze them using the key concept of structural violence. Subsequently, we link the case study findings of vulnerability and inequalities with the sustainable development and human rights discourses. We argue that vulnerability and inequalities are too often taken for granted as an ontological fact. We conclude that the critical disability perspective enables us to radically change our analysis by focusing on the starting point of vulnerability and inequalities.

Case Study: Tonga Families with Children with Cerebral Palsy in Zimbabwe

The case study fieldwork was carried out among vulnerable communities in an extremely poor, rural remote area of the Binga district of the Tonga in the northwest of Zimbabwe on the border between Zimbabwe and Zambia. The people live about 10 km away from the Zambezi River, which reaches inland up to the remote villages in the Chizarire Mountains. Our case study examined Tonga families with children with cerebral palsy in Binga. The Tonga is a matrilineal, ethnic minority group residing in the Binga district, which has a total population of 146,606 (Zim, 2016). It is geographically, socially and politically marginalized within Zimbabwe (Munsaka & Charnley, 2013). Of the 59 districts in Zimbabwe, Binga has been one of the most neglected and lacks essential services such as health, education, communication, and agricultural development (MacGregor, 2009; Mashingaidze, 2013; Munsaka, 2012). It has the highest poverty rate in the country, with 70% of its inhabitants classified as poor or extremely poor (Rural Poverty Portal, 2015). The Matabeleland North province recorded the highest HIV/AIDS prevalence among children, at 3.2% (Zimbabwe Demographics Health Survey, 2015). At 74.3%, Binga has the highest proportion of households that practice open defecation, resulting in contaminated drinking water that causes cholera, diarrhea, hepatitis A, and other infections (Zim, 2019). Only 2 of the studied 53 families had makeshift toilets on their homesteads. Previous literature has reported how hunger and poverty have created devastation in these communities (Mudimba, 2015; Munsaka, 2012) in terms of malnutrition, disability, morbidity, and mortality among infants (Colson, 1970; Muderedzi, 2006; Reynolds & Crawford-Cousins, 1993; Tremmel, 1994). In her study of the Tonga, Maclaine (2006) found that between 85% and 90% were not even self-sufficient during a normal year, and subsistence farming or rain-fed agriculture communities were always at risk of hunger. We selected Tonga families with children with cerebral palsy for this case study due to their profound vulnerability and inequalities (please see Muderedzi (2020) for detailed methodology and ethical issues).

The case study (Muderedzi, 2020) was conducted in all 21 wards in the Binga district and was longitudinal, qualitative, and ethnographic in nature (Sandelowski & Barroso, 2003; Silverman, 2013). The fieldwork took place between 2005 and 2012. The research methods included 53 in-depth interviews in both 2005 and 2012, 20 participant observations, 10 focus group discussions conducted in the local language of Chitonga, field notes, and secondary data. The first cohort (2005) consisted of 30 families with infants with cerebral palsy aged from under 1 to 5, of which 23 died during the first 2 years of the study from malnutrition, diarrhea, malaria, meningitis, and other infections. The second cohort (2012) consisted of 7 from the first cohort and 23 newly recruited families with children with cerebral palsy aged 8 and 13. Thus, altogether 53 families participated in the study. The families were purposively selected on the basis of the following inclusion criteria: (1) being Tonga families living in Binga, (2) having children with cerebral palsy, and (3) having children of the aforementioned age range. In-depth semi-structured interviews were conducted among all the 53 families to elicit information on, for example, their experiences of life before and after having a child with a disability, beliefs and attitudes toward disability, and the factors influencing the care of the child. Participant observation was carried out during a 3-day stay at an informant's homestead with the researcher immersed in most of the daily activities such as fetching water and gathering wild fruits. This observation allowed co-author to meet the extended family and neighbors, especially in the evenings, when disability songs, stories, and life in the Zambezi valley were narrated. The data were translated into English and transcribed verbatim. Data analysis was carried out using the NUDIST (N-VIVO 6) package and the content analysis technique with development of codes (Silverman, 2013).

The Families in the Case Study Experienced Intersection of Poverty and Disability

The studied families have gone through very difficult times and continue to experience profound vulnerability and inequalities today. Deplorable living conditions consisting of poor structures of pole and dagga huts with grass thatched roofs are some of the clear signs of poverty in Zimbabwe. Some interview excerpts depict their daily lives in Binga and illustrate their profound poverty in the remote villages:

> 'I have two children. Four died in infancy. One was bewitched and the others died from the disease. My husband had to take on two more wives'. (Married woman in her 40s)
>
> 'These days we only manage to find enough water for cooking and drinking. Bathing is a luxury'. (Mother in her 30s with a child with skin disease and bouts of diarrhea)
>
> 'My wife and baby died during labor because there was no transport or road infrastructure to the nearest health center (20 kilometers away). . .. My son can't walk. He isn't able to go to school and will never have a job'. (Man in his 30s, with six children)
>
> 'I can't run away from elephants when they attack children going to school. . .We have no food or water to take to school. . .. The school is very far. . .. My parents can't afford the school fees. . .. There are no bridges on the rivers for us to cross safely to school'. (A 10-year-old boy with mobility disabilities)
>
> 'We now have one meal a day. . .. We no longer have staple food like maize or sorghum. . .. We are surviving on wild leaf okra without the starch. . .. We last had something to eat two days ago. . .. We have no proper food to feed our disabled child. He can't chew wild fruits or dried game meat'. (A married mother in her 30s with four other children)

The combination of disability and poverty means the paramount form of inequalities, namely, infant mortality, because as many as 23 families out of the 30 of the first cohort passed away during the first 2 years of the study. Only 3 of the 30 families reported having less food shortages than the rest of the informants. However, neither poverty nor disability can be taken for granted when critically investigating their experiences. We now turn to the history of the Tonga people.

Structural Violence

Disability and poverty in Binga in Zimbabwe are not ontological facts. On the contrary, a number of power relationships and globalization have greatly impacted the lives of the studied Tonga families with children with cerebral palsy. The predicament of the Binga district is largely attributed to the involuntary displacement of about 57,000 people, mostly Tonga, in the 1950s from the ecologically rich Zambezi river plains (MacGregor, 2009; Manyena, 2006; Manyena et al., 2012; Mudimba, 2015).

Even prior to the dam construction, the colonial history of Great Britain overshadowed this area in terms of the growing energy shortage in its copper production and the need for stable electricity. This history is exemplified in the final funding, which consisted of a 28.6-million-pound loan from the World Bank, 28 million pounds obtained from the mining companies and Barclays and Standard Banks, and 15 million pounds from the Commonwealth Development Corporation (Scudder, 2005: 6).

The binational dam was constructed in a very tight timeframe and had not only an environmental impact but a huge social impact on the resettled Tonga people (Scudder, 2005). The governments of both Northern and Southern Rhodesia (current Zambia and Zimbabwe, respectively), without consulting the Tonga community, agreed to the construction of the World Bank-funded hydroelectric power-generating Kariba Dam (Mashingaidze, 2013; World Commission on Dams, 2000). Some of the Tonga population resisted and were killed. Eventually, they were forcibly removed and resettled in arid lands where they could not access the electricity and waters of the Kariba Dam or the wild animal resources in the safaris and national game parks bordering their new villages (MacGregor, 2009; Mashingaidze, 2013). The shortage of large areas of cultivatable land made it impossible for communities to be resettled together, so they ended up scattered many kilometers apart. The wealth of the area was siphoned off to the cities. The government provided the Tonga with basic foods such as maize meal, salt, cooking oil, pulses, or beans for 2 years, but neither the colonial nor Zimbabwe governments compensated the Tonga any further for the forced displacement (Basilwizi Trust, 2004; Conyers, 2003; MacGregor, 2009; Mashingaidze, 2013). Without going into detail, the collapsed price of copper, war and landmines, and government urbanization policy, to name only a few reasons, all intertwiningly affected the deterioration of the economic, cultural, and social situation of the Tonga and continue to do so (Scudder, 2005).

The average cost of electricity in the region dropped by about 30% in 1961–1977, whereas the average price of other commodities and services rose by more than 75% (Soils Inc., 2000 cited in Scudder, 2005). The mining and other industries in both countries benefitted from the dam, as did the government – 80% of Zambia's foreign exchange came from copper from in the second half of the 1960s until the end of the

1980s (Scudder, 2005: 8). Many people in urban areas benefited from the dam at the expense of others, including the Tonga people, who still live in areas with a poor electricity supply. The schools and clinics in Binga started to have electricity in the 1990s. The extremely high infant mortality, one of the negative consequences of the forced relocation, illustrates the great inequalities and vulnerability of the Tonga people, until today. Swift and De Graaf (1994) similarly found that the Tonga community lived in a terrible state, with 60–80% child mortality caused by the lack of vaccinations, malaria, diarrhea, tuberculosis, leprosy, and bilharzia among the adult population. They suffered from acute food and water shortages and are heavily reliant on national and international food aid, resulting in people who do not know their histories and biographies labeling them "donor dependent" and "lazy." This situation prevails, with new infections such as HIV/AIDS and communicable diseases emerging (Scudder, 2005).

The Tonga lamented their destroyed shrines and homes, but most importantly the Zambezi water: "We want our water that we have left behind," to which the white administrators replied, "Go, the water will follow*"* (MacGregor, 2009; Tremmel, 1994). The "River Tonga," those evicted from the Zambezi valley, now aged 80 and above, told us with misty eyes how they were still waiting for the promised water. The same applies to the rest of the communities, who are angry with the government, which claimed to be contemplating sending water to the city of Bulawayo 450 km away. They still remember the huge differences between the previous land and the current one:

> *'We had a good life. The soil was fertile and we had more water than we needed. We grew corn, sweet potatoes, bananas, vegetables and many other crops twice a year—life in the Kasambabezi (Zambezi valley) was good'. (Old grandmother in her 80s, partially blind)*
>
> *'We can no longer perform traditional ceremonies to honour our ancestral spirits (mizimu) – the river connected us to our relatives and friends (bamutala) on the other side'. (Old grandfather in his 80s, married with five wives)*

The Tonga were seldom victims of famine prior to the construction of the dam (Colson, 1971; Natalie & Dayer, 2006; Tremmel, 1994; WCD, 2000). Some Tonga managed to stay or benefit from business opportunities and the water around the dam. Some animals were saved in the name of "Operation Noah" when they caught the attention of the international media during the dam construction. However, the Tonga children did not attract media attention and were left to die (Scudder, 2005). One administrator who took part in the evictions stated: "Their diets changed so much such that there was a great deal of malnutrition and many deaths especially among the children. Many felt totally marginalized and disorientated and it took many years for them to adjust and integrate" (Muderedzi, 2020:30).

After the relocation, poverty served as a social leveler, with little difference in access to mainstream public services among both people with and without disabilities (Muderedzi, 2006). It is not surprising that the Tonga people feel bitter toward the government for what it has done to them. Recent history and current consequences have led the Tonga people to grow into the government's opposition. The government uses their devastating food insecurity as a way to control the Tonga people. More precisely, it sometimes bars food aid from international communities such as nongovernmental organizations (NGOs) in this district. The government's deliberate withdrawal of food aid was noted mainly during elections. The vice president of Zimbabwe stated in October 2005:

> *'We all know that you [the Tonga people] do not vote for the government. As a result, you shall all perish from hunger and the government does not care. I have just come past the grain silos and they are empty. The government will not provide food for you. This is because you vote for the opposition' (cited in* Muderedzi, 2020*:31).*

We observed stunted growth among 37 of the studied children. Some informants reported having undergone several HIV tests anticipating a positive result in order to access food aid from the few NGOs in the district. Only in the mid-1990s did the Zambian government start to support the Tonga people on the side of Zambia in the framework of an established World Bank project. Under this initiative, the Zambian government built schools and health clinics and developed irrigation schemes. Yet the reality of the Tonga families is still extremely harsh, which indicates that both governmental measures and international projects have not been sufficiently transformative. Muderedzi was also disturbed by the government of Zimbabwe when conducting her fieldwork, as they obviously did not want to reveal the profound inequalities and vulnerability in the Binga district. The richer people and foreign investors continue to grab land (Scudder, 2005). Only a few of the Tonga people are employed in unskilled and semi-skilled jobs in tourism around the dam and nearby safari (ibid.) These are only a few examples of the inequalities and vulnerability caused by the asymmetrical power relations between the Tonga and urban people, the government, international development cooperation agencies, and international investors. In other words, stereotypical descriptions of the Tonga as "marginalized, isolated, poor, backward, minority, primitive, and dangerous" (Manyena, 2013:25) need to be demystified.

Decolonial Coping Mechanisms

The Binga district is dominated by the Tonga culture and characterized by political oppression and isolation (Basilwizi Trust, 2004; MacGregor, 2009; Munsaka, 2012). Despite the effects of globalization in Zimbabwe, Tonga's cultural beliefs still dominate their understanding of the causes and implications of bodily impairment (Munsaka, 2012). Even though it has lost almost everything, the Tonga culture has survived and is a strong driving force for self-assertion, resilience, and development. The people still turn to it for answers to experiences of misfortune, such as disease, disability, and death (Muderedzi et al., 2017; Munsaka, 2012; Muntanga, 2001). The perceived causes of disability among the Tonga were their ancestors' sorrow or anger (mizimu), disturbed social relations, and less witchcraft (kuloyiwa) (Scudder, 2005: 2). These perceptions see disability as a curse, punishment, or gift, largely absolving the child and the parents (especially the mother) from taking the blame for the child's disability (Muderedzi et al., 2017). The Tonga perceive disease as a sign of social or cosmic disorder projected on the human body. The most effective prevention against disease and other misfortunes is to properly care for and manage social and divine relations (Muderedzi, 2006; Ingstad & Whyte, 1995; Devlieger, 1995).

The settling of European missionaries in most parts of the country resulted in the conversion of large parts of the population to Christianity. However, the missionaries did not settle in the Zambezi valley due to the harsh weather conditions such as extreme temperatures, little rainfall, and malaria (Colson, 1970; Tremmel & the River Tonga People, 1994). This historical fact has resulted in the Tonga relying on their cultural beliefs without much outside influence (Siamwiza et al., 2013). The matrilineal lineage and clan, along with polygynous marriage systems, are seen as assets that facilitate broad social networks and flexible systems of resource access, helping people meet their material needs (Siamwiza et al., 2013). Their perceptions and treatment of disabled children were found to be contextual and influenced by past and present histories, culture, and low socioeconomic status. Retrospective information on disability was gathered from the "River Tonga" who had then been young men and women, as they narrated their history from the time they lived in the valley to date.

The "River Tonga" recounted how their ancestors used to carry out infanticide but stopped the practice due to high infant mortality as a result of diseases such as malaria, measles, and other infections, which would wipe out some families' children. As a result, children with disabilities started to be taken care of as well as other children. The informants asserted that it was better to have a disabled child than no child at all: "Having a disabled child is a life event" or "it is one of those things that happen in life." They often stated, "a child is a child." Many informants saw similarities among children with and without a disability:

> *'He is not capable of doing anything for himself, but still he keeps us company'. (Parents of a 6-year-old boy with cerebral palsy)*
>
> *'A disabled person can also provide the family with children who in the future can look after themselves'. (Parents of a 12-year-old boy with a disability)*

The Tonga proverb, *Kocilema kunywigwa maanzi* meaning *It is better to be disabled than dead* was echoed among the communities. Informants reiterated that when having a child, they were mainly worried about whether or not the child would survive, not about any possible disabilities. Personhood was prioritized.

Structural violence, resulting in extreme poverty, played a key role in the shift in the majority's conceptualization of disability in the Binga district, though we observed both positive and negative attitudes toward disability among the studied families. Nevertheless, most children were valued and seen as part of the workforce from an early age. This perception rarely attached stigma to disability. The Tonga largely embraced their children with disabilities, encouraging them to do as much as they could. They hoped for a continuation of the family clan. As a result, they saw children with cerebral palsy as persons from birth and took good care of them.

The Tonga people showed strong resilience against the long-lasting inequalities and vulnerability that were manifested in their daily life struggles. *Ubuntu* means "I am because we are" (Bannink Mbazzi et al., 2020). This collective understanding of people with or without disabilities, referred to as "humanness" (Mji et al., 2011), plays a large role in this society.

Lessons Learned from the Tonga Case Study

This case study of the Tonga people indicates, first of all, the globalization of neoliberalism, which has disproportionately impacted not only children with cerebral palsy but also their entire families and beyond. Although the causal relationship between disability and poverty and health is not well-established due to insufficient robust data, Groce et al. (2011) nevertheless identified 27 evidence-based studies that verified a substantial link between disability, poverty, and health. The Tonga case contributes to this theory. The increased pressure of neoliberalism and its globalization have delegitimized disability movements and their collective agency (Soldatic, 2019). This global trend also applies to the collective agency of the families in this particular case study. Inter- and intra-household dynamics and power relationships exist (Groce et al., 2011). Yet, the Tonga case study vividly illustrates the multilayered disintegrations in the lives of the families in the form of inequalities and vulnerability.

The Zimbabwean government ratified the CRPD in 2013 as a member state of the UN, so it is party to the SDGs. International law and policy are not reaching the Tonga due to the profound and intertwined power relationships that favor powerful parties such as foreign investors, the World Bank, the government, and urban dwellers. Disability inclusion continues to remain rhetorical on paper even in the era of the UN CRPD and SDGs and even when the Tonga people themselves treat their children with disabilities as children on an individual household level. The Tonga case shows us some of the global challenges of disability inclusion, even when the historically rooted negative connotation attached to disability is either intentionally or unintentionally minimized at a local level, that is, a human rights-based approach alone does not lead to critique of the global system (Uvin, 2002: 9) or further to a change in the ableist and growth-centered global order (Katsui, forthcoming). Each context in which a human rights-based approach is operationalized encompasses multiple layers of power relationships with local and global fabrics, which are important (Katsui, 2012).

For instance, the CRPD has a standalone article on education (Article 24). It stipulates that "Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live" (Article 24, 2b). When the living environment was as harsh as that in Binga, many households valued personhood much more than the existence of disability. Yet, most of the children with cerebral palsy stayed at home without basic education and often passed away due to extreme poverty. In the Tonga case, many of their siblings also stayed at home without basic education and similarly passed away during the fieldwork. Although the CRPD stipulates that education opportunities for children with disabilities should be “on an equal basis with others in the communities in which they live,” their rights continue to be compromised, because others also miss out on these rights (see Katsui & Chalklen, 2020). In the same vein, the “leaving no one behind” slogan remains insignificant for many families who experience structural violence in Binga and beyond.

Concluding Remarks: Embodied Inequalities and Vulnerability as the Starting Point of Inquiry

How then can the critical disability perspective contribute to the sustainable development discourse in the era of globalization? It is the key question to be answered. The Tonga case study eloquently informs us that at the time of globalization, the multilayered inequalities and vulnerability that are embodied in the lives of individuals with disabilities and their families crystalize the very need to elaborate on them on both local and global scales. In fact, we need to take them as the starting point of investigation rather than take them for granted as basic conditions or ontological facts (Katsui, forthcoming). When we examined the Tonga case from the critical disability perspective, we learned how they have been systematically peripherized and deprived of their power to the extent that many of their children cannot even live their lives. We learned that their poverty, disability, and poor health are not the Tonga people’s fault. The analytical framework of structural violence shed light on the embodied and individualized inequalities and vulnerability and revealed the importance of people’s experiences, and analysis of them helped us understand not only their situations but also globalized inequalities. As inequality reduction is one of the 17 interlinked SDGs, this particular critical disability perspective, as well as a decolonial global South perspective, is useful and usable to remind ourselves to start important analyses with embodiedness (see Rohleder et al., 2019; Russell, 2011; Siebers, 2001). By considering embodied realities, it becomes harder to globally bypass the agonizing and urgent realities of many persons with disabilities and their families, as well as their agency (Katsui & Mesiäislehto, 2022).

Evidence-based scientific studies that prove the deep interlinkage between disability, poverty, and health have started to accumulate (Groce et al., 2011). A longitudinal Tonga case study (Muderedzi, 2020) eloquently supports this theory and further contributes to add the importance of a global perspective to it. A closer look at the Tonga case revealed the non-implementation of disability rights even in the era of the CRPD and SDGs. The globalization of neoliberalism has hit the Tonga people hard, multiple times, over the last six decades, through various power relationships, both locally and globally. Their own transformation and resilience in the form of appreciation of personhood over disability was overshadowed by the globalization of ableism and growthism as well as local politics. It was difficult to realize disability rights through a grassroots-level change alone. In this sense, full disability inclusion in any local context is not only a local but also a global issue, in which the Global North also has stakes in multiple ways.

Our examination of the Tonga people's experiences taught us the significance of taking embodied, multilayered inequalities and vulnerability as the starting point of analysis rather than assumed ontological facts. The critical disability perspective of embodiment enables us to question the system in which local and global fabrics are intertwined and which hinders the full capabilities of the people concerned. This inequality and vulnerability analysis through embodiment is an important point of departure for the discourse of sustainable development, to which we aimed to modestly contribute through this study.

One of the missing layers here is the environmental aspect, which was beyond the scope of our chapter. Now that posthumanism has entered the discourse of sustainable development, human beings are increasingly conceptualized as part of the environment rather than as privileged (Fox & Alldred, 2019). The analysis of embodied inequality and vulnerability that stemmed from the critical disability perspective would similarly contribute to helping us understand the complex relationship of human beings with their changing environment. Climate change and environmental anomalies impacted this multiply disintegrated people with disproportionate force (e.g., Lunga et al., 2019; Omolo & Mafongoya, 2019). These anomalies are an equally important area, through which a critical disability perspective and embodied inequality and vulnerability analysis may contribute to the sustainable development discourse in future research.

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Rethinking Power and the Complexities Between Critical Disability Studies and Decoloniality in Higher Education

20

O. Sipuka and S. A. Ngubane

Contents

Abstract

This chapter explores the intersecting facets of people with disabilities and open distance learning. It examines how the increased decolonization of higher education (HE) and experiences for students with disabilities in a South Africa university can be positively and negatively affected. We relate the biggest issues to the institutional level strategic support, personnel preparation and understanding, policy reflection and planning, inclusive programs, and student engagement. Above all, how disability inclusion drive change is reflected through decolonized

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Student Walk system that has been conceptualized can play a pivotal role in the education of students with disabilities. It found structural discrimination; staff and students alike poorly understood social injustices, suggesting there are more obstacles than opportunities for further decolonization in HE. The chapter suggests that several contradictory institutional support programs need to be decolonized and integrated within inclusive teaching and student support.

Keywords

Disability inclusion · Decolonization · Transformation · Inclusivity · Student support · Student Walk

Introduction

The United Nations Convention on the Rights of Persons with Disabilities defines persons with disabilities as including individuals who have long-term physical, emotional, intellectual, and sensory impairments which in interaction with various barriers may impede their full and effective participation in society equally with others (UN, 2006:1). The South African Constitution (1996) states that all citizens "in theory, have the right to equality and grants disabled people the same rights as all the other citizens" (Heap et al., 2009:858). The Convention on the rights of Persons with Disability advocates the fair enjoyment of all human rights by all persons with disabilities and holds a respect for the intrinsic dignity of all individuals (UN, 2006:1). The University of South Australia concurs that persons with disabilities should not be discriminated against in schools, workplaces, social climate, etc. Disability is a term referring to how society limits an individual's ability based on their disability (DPSA, 2001). As previously discussed by Lorenzo (2011), disability is a common label that can stigmatize and reinforce false stereotypes, particularly where students with disabilities are treated as being not as competent as their peers or the impairment as a "disgrace." Lorenzo (2011) also finds that students frequently counter negative assumptions about their disability with their own positive self-perceptions.

Confidentiality of disability disclosure by students is essential and is often voluntary. Studies have shown that people with disabilities could be intimidated by the prospect of revealing their health details to the authorities (Burgstahler, 2008). This avoidance also follows students because of the stigmatizing of students with disabilities; for instance, a student who has epilepsy will not be relaxed in university as he/she fears losing friends because of stigma. Students with more visible disabilities may have difficulty revealing these issues. Picard (2017:1) states that students can disclose a disability, such as epilepsy or a chronic pain condition, without needing to provide it to others. The so-called "hidden" mental health problems may be hard for students to reveal because many may believe that they are safe if they look good. In certain cases, a student may exhibit unusual behavior which may be linked to their impairment (Walters 2010:428).

Scorgie et al. (2010) argue that physical impairments lead to derogatory views of people with disabilities. This is similar to how people who use wheelchairs may be subjected to being labeled as having an intellectual disability. Beyond physical appearance, students with concealed disabilities also confront other students who might dismiss their impairment by saying, "You look fine." Picard (2017) argue that the average undergraduate appears to rate an individual with learning difficulties as less able to learn. They note that some educators believe that students with learning disabilities can perform at lower levels than their peers. Despite having learning disabilities, students can learn new knowledge as long as they acquire, process, store, and/or react to it differently (Picard, 2017:1). There are many gifted and talented students with disabilities, just as there are among other groups of students. Bley and Thornton (2001) argue that disability should not be an obstacle to gifted people with disabilities as it offers no factor restricting their capacity. In the philosophy of education of students with disabilities, cultivating and accepting the gift in the student is far more important than placing the student down in the field where the student is poor because giftedness is often ignored in students with disabilities. Acceptance of one's special abilities and supportiveness is important to mitigate the effects of a disability. HE ought to be able to consider the individual needs of each student by recognizing their abilities and impairments. The learning environment needs to be attentive and motivating, as this will allow for the best learning experience.

Decolonization is a process to repair the damage caused by colonialization. Maldonado-Torres argues that decolonization is disrespectful because it casts doubt on the legitimacy of the colonial context. The decolonization strategy included a plan to change the colonial situation. In HE, it is even more important today that an Afrocentric but culturally and globally influenced awareness is needed so that institutes of learning remain the cornerstone of transformation, reform, and progress. The critique of decolonization deconstructs the consequences of colonization and its coerced foundational structures. It understands the developed abilities to explore indigenous knowledge structures (Alfred, 2008). Those who apply a decolonization analysis are likely to be more accessible to other learning contexts and speculations. A decolonization review looks at how imperialism affected the Indigenous peoples of the region. Decolonization is an act that draws in imperialism and colonialism at many levels. A second concern is that expansionism and dominion frame those as less deserving and capable. As a result, although colonialism continues to exist today, it has discovered ways to be more covert in its dominance over and erasure of Indigenous people. Throughout history, colonialism has manifested itself in various forms of systemic oppression as well as educational practices and policies in HE institutions (Arvin et al., 2013). This highlights the importance of indigenous traditions and the influence of colonialism in combination with colonial structures. A decolonial approach provides an ideal means to thoroughly analyze the effects of colonialism.

Disrupting hegemonic understandings of disability can be accomplished through the critical disability studies (CDS) and critical race theory (CRT) (Crenshaw et al., 1995). Disability studies (DS) have long been criticized by racial minority voices in the disability community for universalizing a white experience of disability as the default norm and failing to include the experiences and meanings of disability for persons of color (Erevelles & Minear, 2010). At the same time, CDS observes a glaring absence of disability inclusion in CRT (Annamma et al., 2013). Nonetheless, it is beyond this paper to comprehensively explain the junction of CRT and CDS viewpoints.

However, the primary implication of CDS for the decolonial project is that it provides epistemic resources for understanding coloniality as enabling and disabling people to take part in society. In the aftermath of colonial violence that gave rise to the modern order, HE is endowing with capacity for action, freedom from constraint, and scaffolding for (over)achievement that people in these settings understand as the full realization of natural human potential. A process of disablement or coloniality of being (Adams et al., 2018) is inextricably linked to this process of modern enablement: the destruction of community, the expropriation of means of production, and the consequent reduction in the capacity of the subordinated majority to meet environmental demands and to achieve even the most modest aspirations. Thus, colonial violence caused disablement not just by producing bodily damage, but also by placing restrictions on people's ability to act and accomplish their full potential despite their inherent abilities.

Psychology's hegemonic conceptions on enablement hide the cultural-historical architecture that supports it and instead portrays ability as an essential individual trait, a sign of merit, and the basis for the allocation of rewards. In a similar vein, hegemonic global institutions' decoloniality is a groundbreaking way of cultural advancement, which is elevated to the level of a standard for universal emulation. By framing inequality as the just-natural product of intrinsic distinctions in merit or deservingness, both types of hegemonic understanding help to cover up or legitimate colonial injustice. CDS perspectives shed light on the cultural affordances that serve as the foundation for otherwise naturally occurring abilities. Consequently, the performance of persons in dominant positions is not simply the natural product of greater talents, but also serves as evidence of their value and an explanation for superior outcomes from this perspective. Instead, their performance is aided by epistemic and material investments that serve as performance-enhancing devices, artificially inflating their outcomes in ways that, if one were to think otherwise (Escobar, 2007), one's conclusion may be illegitimate.

This is why global citizenship and associated dialogues on globalization are often problematic because of the ethical liberal reaction to the expanded notion of ethnicity, class, sexual identity, transient, and ethnic inequality (Ormrod, 2008). This frequently imported liberalism lives awkwardly and directly close to widening politically and religiously invested social and religious polarization, diligent and malicious levels of destitution, worldwide violence and conditions of war, widespread hardships of the population, and mass displacement, among others. It incorporates an accompanying ascent in cosmopolitanism and world traditionalism alongside new discontinuities and reconciliations as the political territory shifts under the economic troubles, where innovation and private enterprise are alternatives.

With the emergence of humanism and philanthropy comes a revival in humanism and philanthropy (Gonzales, 2012). While humanism opens the door to an individual's well-being, that individual's well-being faces a long-term sustainability risk in the absence of philanthropy. Nonetheless, while philanthropy can help, aid, and support people on its own, it will be less effective if it is not accompanied by empathy. As a result, humanism is required in philanthropy to empathize with and comprehend the true needs of people, rather than making assumptions about what will work best for underprivileged people. Reflecting on this topic from the HE specifically, perspective in recent decades, global citizenship discourses have been taken up with some force in policy documents and studies, vision articulations, HE and tutoring, and studying curricula documents within Western-based structures. They have also invaded and become increasingly common in educational settings.

These discussions allow local responsibility for and understanding global interdependence and mutualism. Under globalization and monetary progressivism, the world that these talks proclaim seems incontestable and lives in the judgement poisonous and soiled order of things that make choices improbable and unreasonable (Bourdieu, 2002). It is, however, imperative to point out that in the globalized information and knowledge economy, there are questions about who takes the interest, when, what they focus on, and how getting enrolment rates up in HE can contribute to societies' economic and social growth and improvement and consequently lessen destitution (Olukoshi & Zeleza, 2004). The 2009 World Conference on HE in Paris discussed the importance of reinvigorating HE in Africa – a critical tool for the growth of the continent (UNESCO, 2009).

Since then, the current problems and prospects for the future of regionalization of HE are inextricably linked to these historical settings as well as the institutional dynamics of both regional and subregional institutions (Woldegiorgis, 2017). However, even if domestic dynamics within the African HE landscape play an important role in regionalization processes, the majority of HE regionalization initiatives are affected and driven by global policy changes and international actors to a certain extent, which may affect inclusion directly.

All in all, factors such as poor communication and commitment to policy changes, disproportionate reliance on external funding, wavering commitment, fragmentation and duplication of processes, and the lack of a participatory nature of the policy in terms of engaging all stakeholders are cited as reasons for the slow implementation of regionalization in African countries (Woldegiorgis et al., 2015).

However, there is some work to be done to ensure that broadening the interest of regionalization is not just a question of "a flood of students into increasingly broken organisations" (Yusuf et al., 2009:110). Equality and inclusion are not only about increased acceptance of disabled students but also a deeper sense of social citizenship for disabled students (Barnes, 2007).

In response to Barnes (2007), it has become increasingly clear in the recent past that the essence of educational regionalism happens when institutions of various profiles and levels of education begin to focus their work on regional requirements and are then integrated into regional socioeconomic systems (Shannon & Galle, 2017). For education decolonization or regionalization, the following are essential components: an emphasis on the needs of individuals as they are manifested in the local social context; the identification of concrete regional features in education system activity organization; development of spheres and directions for vigorous and inclusive education system; and the development of training program structures and courses that are geared toward learning about a particular population or group.

These opposing viewpoints can be seen in the many educational policy frameworks that deal with internationalization. In the twenty-first century, the adoption of the Convention on the Rights of Persons with Disabilities (CRPD) by the United Nations General Assembly on December 13, 2006, was a major event. Both the CRPD and its Optional Protocol went into effect on May 3, 2008, marking its one year anniversary. Although the Convention does not define disability specifically, it acknowledges the following:

> as the idea of disability evolves, so does the way people with impairments interact with attitudinal as well as environmental barriers that limit their capacity to participate equally in society on an equal level with everyone else. (UN, 2016, p. 1)

An inclusive society can only be achieved through implementing inclusive education as a means, not an aim in and of itself. That is why anybody advocating for inclusive education has a stake in dismantling obstacles that exclude people based on race, gender, or any other characteristic.

Decolonization in HE

Decolonization promotes the incorporation and inclusion of students with disabilities in the education system as the way toward understanding and eliminating obstacles in facilitating equitable access to HE (Heap et al., 2009). Similarly, a selection of students with disabilities does not lead to greater support or college life and student relations. Access to finance needs to be followed by some assistance, but not too much, to achieve in the field (Ormrod, 2008). There is a need for uniform guidelines and procedures to embed disability into all programs and planning (Picard, 2017:12). In the global HE inscription, how students manage the state of becoming incapacitated with both attitudinal and physical challenges is lacking (Ritskes, 2012). A study in sub-Saharan Africa has yielded comparable findings (Scorgie et al., 2010). The low intention to make educational systems and programs more available and minimal scholarly and non-academic support build obstacles to the retention and achievement of students with disabilities (Scorgie et al., 2010).

It is only through the acknowledgment of cultural differences that cultural diversity may be embraced into HE. Students with impairments are seen by some educational models to be capable of engaging in meaningful learning experiences (Shannon, & Galle, 2017). HE programs all over the world are now accepting and enrolling more persons with impairments, even those with severe disabilities. New methods of teaching and training focus on supplementary, targeted, or personalized support, considering the essence of any weakness or strength. These programs, on the other hand, promote provision rather than assurance (Gaztambide-Fernández, & Murad, 2019). As the world gets more interconnected, so does the demand for more prestigious HE institutions with a diverse student body. Race, gender, and curriculum classes occur once an organization emphasizes inclusion" (Gaztambide-Fernández, & Murad, 2019:7). Democratization of the learning environment and the learning content puts emphasis on the following attributes: (i) adult education which is part of lifelong learning, (ii) technological developments that emphasize the introduction of new technologies in every sector of education which are radically and constructively changing the entire landscape, and (iii) the dynamics of heterogeneity that relate to human society and the sharing and exchange of information leading to knowledge which are the building blocks for its development and prosperity. The unique characteristics of individuals with disabilities along with the advancements and innovations in these areas of inclusion could provide a new impetus to the inclusion provisions of HE. It is feasible that this type of student will be included in an educational setting that is non-offensive, meaning that diversity is noticeable.

Our contribution argues that HE system decolonization is revealed in teaching method, research, and administrative areas. Many institutes now focus on post-colonial settings and how rights can be granted to historically marginalized citizens. The chapter explores current and past thinking that emphasizes the basic features of individual support for students with disabilities. In a separate study, Sipuka (2020) argues that student support is ad hoc and institutionalization of inclusion across the entire University is more theoretical than practical.

Decolonization and Transformation of HE

Decolonization is a useful mechanism from which to examine the change facilitated by the HE sector. This chapter calls for a more progressive change in the education system as implemented around the world. Ndlovu-Gatsheni (2017) highlights the importance of appreciating decoloniality as a mechanism that can allow and liberate thinking and practices that spur on possibilities of other knowledge and worlds. He writes that:

> At the epistemological level, decoloniality is about disobedience to the norms and practises of epistemological, ontological, and metaphysical norms. At the political stage, there are new critical approaches, new analytical tools, and new praxis directions. In resistance to the awareness of equilibrium and typical methods that function as part of colonial matrices of control. (Ndlovu-Gatsheni, 2017)

> The need for education transformation arose from the view that what is required to drive existing debates on decolonization in HE is expressions of enactments aimed at undermining dominant power structures and institutional cultures to shed light on democratized traditions and spaces that bring to the fore previously marginalized voices and information. For transformation and renewal activities to be impactful in the academy, we can, alongside students students, by criticism contribute to the self-clarification of the struggles within our

> universities. Such introspection and debate could reveal how, in epistemic terms, the "systemic anchoring of socio-economic disparities and discriminations" in institutes are, in part, constituted and reinforced by the daily habits of individual social agents.

To incorporate the aims and efforts to promote a reconsideration of "decolonization" in university education and society, scholars are challenged to be skeptical of theorizing which has been distilled into propaganda, to question certain demands to decolonize HE which themselves are steeped in power hegemonies, and thus to advance emancipatory praxis in HE contexts specifically, which then influence deep changes across the education system from ECD, schooling, tertiary, and lifelong learning. Such context also advances the notions of egalitarian epistemologies and social justice. The authors included here each present a unique critical stance on interrogating efforts to "decolonize" education, which foreground a social justice orientation and practicality, thus contributing valuably to current discourses in the broader field of the transformation of HE, specifically in decolonization. The series of 12 studies shifts the emphasis from theorizing decolonization because of a critical study of its implications for promoting HE pedagogy and praxis and influencing curriculum growth (Mahabeer, 2018; Mampane et al., 2018; Sathorar & Geduld, 2018). These authors highlight the democratization of knowledge among students and the disruption of existing power structures in HE.

Two prominent academics provide unique perspectives on the role of student voices in shaping education reform (Cherrington, 2018; Stuurman, 2018). Though McAteer and Wood (2018) address the civic position of the university through positive community engagement, other scholars showcase how decolonization-in-praxis can open possibilities for fostering inclusive classrooms and universities (Mfuthwana & Dreyer, 2018; Muthukrishna & Engelbrecht, 2018) in South Africa. They end with a reflection on efforts that could threaten institutional spaces and democratize expertise in academia (Walters, 2018). Michalinos (2018) explores the potential for transformative possibilities of decolonial theoretical ideas with the notion of "humanizing pedagogy." The article's primary focus is on the relation between humanization and decolonization in HE and the implications these have for pedagogical practice. He argues that there is a crucial need for institutions of HE in South Africa to focus on why they should decolonize pedagogies in knowing and knowledge-making. This research shows that an informed post-colonial pedagogy can be reconceptualized within the decolonizing and transformative context to challenge current colonial powers within the academy. This study challenges HE lecturers, academics, and researchers to interrogate the latest Eurocentric pedagogical methods by building on and twisting these very practices.

The next discussion moves the emphasis of decolonization from theoretical debates to case studies that demonstrate the importance of considering the personal opinions, motivations, and perspectives of students and scholars on how to change education systems at the curriculum level. In certain cases, however, they are not inclusive, which this chapter aims to discuss in the future. Student views on decolonization of HE, as well as the role of socioeconomic change in the design of new national qualifications in the Adult and Community Education and Training

Sector (ACET) have not been sufficiently incorporated. Mampane et al. (2018) address issues of indigenous awareness, culture, literature, technology, and discourse within HE in Africa. Their study analyzed the decolonization of education and the use of students from Africa in their research. The study showed that students view decolonization as a means of resolving historical injustices and marginalization by simultaneously valuing and exploiting indigenous languages and culture while incorporating relevant and cost-effective technology: in other words, the best of both worlds, the past and present in service of a better future.

The focus of Ismail's project is on the Adult and Community Education and Training Sector (ACET), intending to create new national qualifications for ACET to respond to the needs of the adult education community is a case in point. In designing the qualification, they attempted to incorporate new criteria, vital transformative instructional practices, feedback from community educators, and student views on a decolonized curriculum. Ismail (2018) asserts that these structures contradict one another particularly in a capitalist environment in which education is narrowly conceptualized as preparing students for the workplace. Ismails' (2018) project aimed to include in the certification new policy requirements, transformational educational methods, and viewpoints from community educators, as well as current requests from students for a decolonized and inclusive curriculum while designing this degree.

Another case by Mahabeer (2018) described the rapid changes that have occurred in HE in South Africa in the past 20 years. The contribution notes that even though South Africa is committed to reform, it is continuing to enforce standards and specifications which are foreign. The author suggests that there is a need for curriculum evaluation and that Pinar's approach should be used to evaluate an inclusive curriculum. She appreciates that the traditional Western way of thinking is being challenged by changing perspectives on the curriculum. Mahabeer's (2018: 1) research finds that "curriculum decision-makers are neither complacent nor at the mercy of Western awareness and ideologies." The decolonization of the curriculum is discussed through a case at a university in South Africa. Mheta et al. (2018) assert that the University of South Africa UNISA as an ODeL university remains Eurocentric and suggest that decolonization is necessary to address this imbalance. They suggest a way forward by exploring various options and ways of (re)thinking university curricula and open the debate for further discussion on this seminal subject, not only for UNISA but for all HE institutions.

Similarly, Cherrington (2017) aimed to provoke action in a teacher education program through the strategic use of hope. Key transformative research shows how incorporating hope directly into discussions with student-teachers about becoming agents of change had a positive transformative value for the participants and therefore implications for HE revitalizing initiatives. Cherrington (2017) proposes that the perspectives of student-teachers need to be valued as a viable means for empowering learners. Therefore, until this point, there is a need for education decolonization. She stresses the importance of critical thinking regarding university decolonization initiatives, calling on students to think critically and make a social impact.

Pragmatics of coloniality is inherently linked to a university's mission and character, as well as the way it engages with its internal and external cultures. Cajete (2015) and Coulthard (2014) call on the university to work on concrete community initiatives. The advocacy is for building more alliances with communities to achieve change and social justice. With a participatory action research project investigating university-community cooperation, the authors argue that when university researchers step away from seeing themselves as "experts" to instead seeing themselves as "facilitators," the process of information creation and democratization is improved. Coulthard (2014) shares a unique insight into rethinking the relationship between universities and their communities as one of epistemic democracy, which can meaningfully contribute toward mutual understandings of decoloniality and sociality.

The pragmatics of coloniality is intricately related to the function and character of the study units and how they interact with their internal and external scholarly cultures. McAteer and Wood (2018) propose that the university needs to engage in community-based initiatives. They argue that alliances and collaborations with communities need to be core to the university's transition and social change efforts. In a participatory action research project examining university-community cooperation, the authors propose that when university researchers see themselves as "facilitators," their participation would be more successful and thus the process and products of information democratized. McAteer and Wood (2018) further provide unique insight into the possibilities of re-imaging a university in relationship with its society as a place of epistemic democracy, meaningfully contributing toward mutual understandings of decolonisation and social justice. It is also imperative to apply concepts discussed to education outside the South Africa context. The chapter focuses on the generation of education transformation into the institutes and inclusivity. Scholars feel they have difficulty enforcing the policy of inclusion in HE since it comes from the North and is poorly transposed to the South. They recommend rethinking the current delivery of quality education for students with special needs in under-resourced South African universities.

Muthukrishna and Engelbrecht (2018) utilize 5 years of research documenting political advocacy for inclusive education in Southern Africa. Amid these tense and nuanced issues, they propose a vital, inclusive curriculum that is aimed at anti-oppressive social justice. They emphasize the need to provide teachers with the skills to recognize, analyze, and assess the ethical and social consequences of inclusion pedagogy. Furthermore, Muthukrishna and Engelbrecht (2018) revealed that HE is critical in ensuring that people with disabilities have equal access to good jobs and a fair social standing. Higher learning institutions need to broaden knowledge and understanding of the broad perspective of achievements and experiences of this group of students in HE and to compare them with those of students without disabilities. This is especially true now that legislation has been passed to support access to HE and attitudes toward people with disabilities have changed.

In their article, Muthukrishna and Engelbrecht (2018) assert that quality education needs a critical structure for disputing decoloniality and inclusive ideology. Mfuthwana and Dreyer (2018) examine how inclusive education policy is poorly communicated by various stakeholders. Via a series of interviews, this research explains the difficulties teachers have in integrating multicultural education in South Africa. Although the teachers mostly agreed that there is a shortage of training and support, the authors criticize that through not considering local contextual factors brought about by colonialism and apartheid legislation, any attempt to better implement inclusion in the HE environment would be ineffectual and would only perpetuate inequalities. Although Mfuthwana and Dreyer (2018) suggest universities need to be more assertive in internalizing and mandating transformation pedagogical and organizational spaces for driving decolonization, Walters (2018) believes that "mainstreaming" such initiatives will bring about control rather than turbulence. Walters also discusses strategies for navigating the "in-between" spaces for transformations within the academy. Her study details two instances of the University of the Western Cape questioning traditional institutional culture and hegemonic power relations and brings them to a "decolonized university." Walters's (2018) critique of these events affirms that developing alternate institutional procedures is a vital component of decolonizing education.

However, unit-based initiatives to transform the university were combined into the teaching and learning unit. Therefore, Walters cautions that much can be lost when every program is decolonized from within rather than given its room to thrive. Together, these elements highlight some major concerns that must be addressed as we strive to dismantle colonized cultural systems and promote a social justice orientation. The chapter explores possibilities in changing the information system, reshaping institutions, and envisioning education transformation as a phase of humanization.

Transformation and Inclusive Student Support in HE

Inclusion is about the university structure, learning environment, and curriculum so that all students can work together successfully. An inclusive classroom is described as a learning environment that provides a welcoming learning environment for all learners, including those who have learning disabilities. Inclusivity recognizes everyone, including those of different backgrounds and cultures. By teaching our students the value of acceptance, we will build a more inclusive and understanding atmosphere in all universities, in society, and beyond. An inclusive university can only be effective when every student feels included and connected to the university. We argue that it is in the peculiarity of professional preparation, with its high demands of both theory and practice that creates specific challenges for students with disabilities, thus the need for the development of self-advocacy for students with disabilities, continuous institutional and social reform, and greater research into the experiences of students with disabilities studying for professional degrees. This can only happen through free, frank, and respectful dialogue about differences and current situations, an open, welcoming community where everyone feels valuable and respected. Change in inclusive education, teaching, and learning in HE has embedded strategies for developing course materials and methods of delivery to include all students in meaningful learning. This fosters a sense of appreciation for the individual and their community, which can enhance their lives and learning (Quinn & Vorster, 2016).

Tait (2003) claims that institutional support provides a positive learning environment that encourages student success and also institutional growth. He suggests that an approach focusing on three spheres, cognitive, affective, and systemic support, will be more beneficial (Tait, 2003). Cognitive support improves academic skills, while affective support provides students with a desire to learn. The method assists students in recognizing and dealing with institutional laws and in knowing how to use learning structures in a way that achieves competence. Students who receive help from administrators experience institutional success. He also maintains that increased institutional support decreases the dropout rate. Vorster and Quinn (2015) recommend that the addition of student support resources to the teaching and learning process could result in their being ignored in curriculum and evaluation design processes.

Non inclusive learning climates in HE harms students with disabilities. The World Health Organization (WHO, 2001:214) asserts that obstacles are “actors in a person’s environment that limit functioning and create impairment.” The WHO (2001) divided environmental factors into five groups and how they affect the participation of students and staff in HE (Fig. 1).

In congruent to WHO observations, the CDC (2017:1) notes that the burdens of people with disabilities are exceedingly difficult to overcome. Students with disabilities can compete directly with other students for college scholarships. In some countries such as the United States and the United Kingdom, studying is provided in a way that depends on how much money the student has access to. These federal government grants allow students with disabilities to achieve their full potential. The

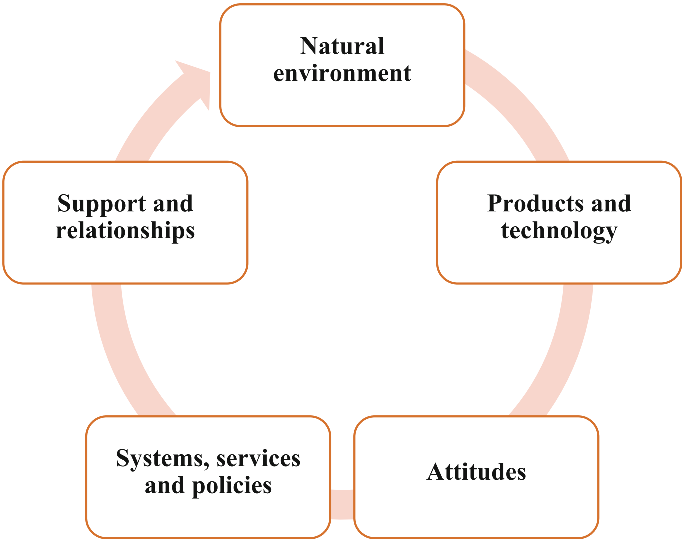

Fig. 1 Environment factors that may influence learning in HE. (Source: WHO, 2001)

research on student support services shows that decision-making on whether to use different student support services was guided by several factors, such as the current climate of transformation, inclusion and disability policies, various support structures, and funding. There is, however, caution regarding finding a comprehensive road map to boost student support programs in HE (Tait, 2003). Because of the unique nature of each organization's or institution's belief system, all organizations can have support facilities.

Our contribution provides a way to investigate the needs of students with disabilities and the educational ethos of UNISA**.** This chapter is drawn from many years of experience as a member of staff interacting at different platforms advocating for inclusion, as well as my recent PhD research on the related matter. The choice of UNISA is based on its size as Africa's largest ODeL university whose role in the decolonization of HE curriculum has become increasingly important. Moreso, how such a mega none contact university deals with issues of inclusion in its decoloniality efforts raises significant interest in the topic.

The Case Study of the Inclusive Student Walk at UNISA

The history of UNISA dates to 1946, with the founding of the world's first college dedicated to distance education (Le Grange, 2016). UNISA is in the nation's capital, Pretoria. UNISA has long been the largest provider of studying opportunities in South Africa, and during the politically enforced era of racial discrimination, it continued to serve black students without regard to ethnic or racial classification. Seedat (2018) explains that the university aimed to resolve issues of social equity as the Afrikaners defined it. The Afrikaners felt discriminated against by the British in South Africa when the HE system was first established in the country. UNISA used to provide university education to Afrikaners at their farms all over the country because of the Afrikaners being farmers and ranchers. Unfortunately, the experience many Afrikaners had in South Africa did nothing to teach them about the violence or exploitation of others.

Paradoxically, and incomprehensibly, UNISA provided learning opportunities to many black and colored students, many of whom were previously excluded from educational opportunities, even as they had been excluded from political rights (Engelbrecht et al., 2016). To increase access and combat the suffering of students, the Office of the Registrar deemed it appropriate to draw up a user-friendly framework that would assist students in finding help within the respective student support units. The framework is called the Student Walk (Student Walk, 2016/17). This Student Walk model has generated a great deal of rhetoric and debate about the intention to be more inclusive. In consideration of the commitment of UNISA to students with disabilities, a directorate called the Advocacy and Resource Centre for Students with Disabilities (ARCSWiD) was established in February 2003. The directorate profiles students with disabilities, as well as providing targeted support for them. ARCSWiD uses creativity to deliver its core functions, specifically the production of study material in alternative formats and the facilitation of needs-based support regarding teaching, learning, assignments, and assessment.

The case study examined factors influencing inclusiveness within the Student Walk, which involved in-depth exploration of a specific setting or context of the UNISA Student Walk model. A phenomenological approach (Yin, 2009) was adopted to allow several participants to explore their lived experiences. Creswell (2017:99) describes a case study as an "empirical inquiry that investigates a contemporary phenomenon in depth within its real-life context."

The case study comprised data collection from students and the staff of South Africa's oldest university, namely, UNISA. Owing to its approach, it is assumed that UNISA as a university without walls can be more inclusive and accessible than mainstream academic Institutes (UNISA, 2018). The case study generated several policy areas which are summarized in the sections below. for instance, for programs benefiting students with disabilities, data shows that there is inadequate institutional support in place for integration, decolonization, teaching and student support.

Although an inclusive study is carried out every year, its efficacy and the problems it poses to ARCSWiD and other UNISA personnel have not been investigated, particularly its examination into the assistance offered to UNISA students with disabilities. The key research gap by Sipuka (2020) was the need to examine how students with disabilities are accommodated through the UNISA Student Walk model for decolonizing the university.

The understanding of current student support programs, the importance of reviews, peer mentoring, and non-academic counseling methods is underscored. Since student support services are not well organized, those students qualified for these services are seldom aware of them. Another belief is that the expansion of online service hours and funding for students with disabilities is insufficient and unrealistic, particularly when inadequate Internet connectivity and accessibility related to computer technology and online learning negatively affect those on the autism spectrum. The study showed that there is presently no plan in place to include decolonization in any student support. The Student Walk model is intended to provide adequate student support for all students who needed assistance from application, enrolment, orientation, and throughout their study period. Unfortunately, this assistance is hardly rendered. For its progress in decolonization, the project lacked inclusivity, inadequate conceptualization from the beginning, and the exclusion of students with disabilities. This was combined with a weak understanding of the problems and needs of the students with disabilities, along with their needs for the model. Findings reveal that reveals that the university has insufficient tools to address racial disparities and how to decolonize.

Another hurdle at admission for students with impairments is the tension between impairment and disability. The two are considered together as a social construct by critical disability studies, whereas they are truly separate. Decolonial theory helps us comprehend the conflict between impairment and disability in light of the structure of society using "normalcy" as the standard. However, students may continue to face discrimination in HE if the root reasons for the barriers they face are not made clear to them and the relevant stakeholders. Getting rid of obstacles necessitates being aware of their root causes.

There is an undeniable divide between disability and curriculum as such curricula were not adapted to the student's respective disabilities; more specific was that teaching and learning methods are not accessible to all disabled students depending on their impairment needs. The Student Walk was designed so that students with disabilities could be supported and to also serve as an example for pedagogically sound inclusive curriculum development. The responses showed that the decolonization of HEIs will restore the ideology of HEIs. Until HE becomes aware of the root cause for the barriers students with disabilities face upon entrance, it will be impossible to remove inequitable behaviors and systems. As a result, "treating the underlying cause" would mean bringing together all oppressed social groups and non-disabled people who are also battling oppression to engage in coloniality. The characters, legends, and various sources of knowledge are an integral part of a typical curriculum decoloniality. That may change both the students and the faculty by affecting both the teachers and the students. This may not be a fast shift, but it must be addressed to be timely and efficient.

When considering decolonizing the curriculum, one must recognize that the present curriculum is not viable because in the critical disability studies (CDS), students are increasingly taking up these themes in their coursework. Similar to how CDS developed from previous conflicts, CDS is now tied to the workings of ableism as a "socially designed complex machine of disempowerment which connects with, and is just as widespread, as many oppressive institutions" in its struggle. Instead of following the linear narrative of progress, CDS proposes "alternative temporalities" that challenge "ableist notions of 'normal' [academic] orientations and periods" (Lega, 2021). Disability studies' Eurocentric character is denounced, and study on the experiences of students with disabilities in developing countries is included. Therefore, HE should address this question and call upon colleges and universities to help facilitate positive systemic change.

One of CDS's goals is to make life better for everyone, especially the devalued and mistreated individuals with disabilities. Those who support CDS are post-conventionalists, post-structuralists, and postcolonialists who, among other things, are critical of ableism and disablism and want to develop a new understanding of disability in light of intra- and/or intersectionality, suppressed voices, and recognition of difference. What's most noticeable by the CDS proponents is the desire to broaden perceptions of disability outside the Eurocentric Global West. Decolonizing disability may be possible if we view it from this perspective. People with disabilities and other marginalized groups will be made aware, liberated, and given agency as a result of this initiative.

Regarding the prospects for and obstacles to the decolonized curriculum, it has been found from the study that decolonization is not well understood by both staff and students; there are more barriers than opportunities. Although HE in South Africa enjoys intellectual freedom, most of the ODeL curricula perpetuate Western philosophies and ideas that perpetuate the hegemonic state of information, education, learning, and study as this was noted by the CDS. Western influence can be seen in how programs or policies are designed. Eurocentric information institutes continue to inhibit graduates from entering the market by forcing them to take jobs within the status quo. Transformation to create an inclusive curriculum has been feared as a wasted opportunity. Barriers to inclusion, including insufficient government and legal aid, facilities and equipment, skilled personnel, teacher development, instructional skills, adaptive teaching methods, supportive management, and cultural attitudes, have been identified. Staff and student experiences suggest that it may be more beneficial to find methods of identifying and expanding already positive inclusive education practices than focusing on vulnerabilities. Focusing on factors within the physical and social environment will reduce the extent to which further additional support is required and allow the implementation of individual support to be minimally intrusive.

Addressing Structural Discrimination and Social Injustices in HE

UNISA needs to pronounce itself regarding the practical implementation of regulations about inclusive initiatives with decolonization with disability inclusion in mind. Specifically, a clear policy on support of students with disabilities is developed by universities, with the aid of organizations working with people with disabilities, students, and other key stakeholders. To enhance the chances of success of the Student Walk model, the policy needs to:

(i) Indicate how information about disability can be used.
(ii) Stipulate how various university divisions can offer support to students.
(iii) How teaching and learning services can be strengthened to make it simpler to use the system.
(iv) Stimulate research on the success and completion rates of students with disabilities the university enrolls.
(v) Explore ways to adapt programs currently inaccessible to students with disabilities, these from a decolonization perspective.

While such a plan will not ensure that students with disabilities be enrolled and engaged in HEs successfully, it would still be a significant initial phase toward presenting both students and organizations with a starting point and structure to continue to tackle current gaps in participation as well as in the inclusion of education and learning.

These policy imperatives are summarized in the model below:

To understand the application and interconnectedness of pillars of the Student Walk model to inclusivity in a HE environment, They are briefly discussed below:

Institutional Level

At the institutional level, issues of decolonization which offer an inclusive approach to teaching and learning processes within an ODeL environment would require inclusive support from all faculties, centers, schools, and institutes within the university. There is a need to rethink the direction of decolonization from different department levels and ascertain its relevancy and trajectory toward curriculum revision in an inclusive approach. It would also be necessary to re-look the admission to various programs within the various institutional universities, especially those that alienate students on disability grounds. Sound career guidance and counseling services need to be provided so that students understand the course requirements at the admission level as well as the foreseeable challenges. Institutional barriers toward academic and professional development entrenched in an inclusive approach should be investigated.

Further issues that require consideration at an institutional level are the underrepresentation of staff members with disabilities in charge of student affairs; the limited awareness of most of the staff members of the issues of diversity and cultural sensitivity and an overall understanding of disability issues; and finally, the relevant pedagogical approaches that should be adopted. Curriculum design and redesigning are culturally and institutionally sensitive and require a firm commitment and professional dedication. A university comprises several campuses, institutes, or departments, and together they strategically maintain an organic control that significantly warrants strategic debates and discussions about curriculum redesigning and inclusivity at large. An institution needs to realize its role in diversity and inclusive curriculum redesigning.

Inclusive Policy and Practices Initiatives

It is important to ensure that inclusive preparation is adopted at all levels of national policies and guidelines. The legislation holds that all people are deserving of inclusive education. In cooperation with disabled persons' organizations, NGOs, parents of children with special needs, teachers, and others in the community, comprehensive education policies and guidelines must be instituted. Often findings claim that university inclusion policies remain vague, uncompromising, and optimistic. The multicultural programs are not directly linked to any public policy. Students have negative perceptions about the value of inclusive student support programs.

There needs to be systematic policies and guidelines in place to support inclusion and those that create a conducive environment for innovation to produce a curriculum that is culturally and institutionally relevant. The institutes need to review diversity and inclusion, not only regarding the number of students enrolled with disabilities but also a fair and conducive environment for learning for students with disabilities. This would require early inventory into the comprehensive barriers to enrolment and throughput on certain programs by students with disabilities. Without such a broader understanding of students' challenges, it would be difficult to devise inclusive initiatives. Whereas several initiatives are inclusive, apart from the enrolment, there are noticeable gaps throughout the tenure of the students on certain programs during assessments. Such comprehensive initiatives would entail a detailed examination of learning materials, the forms of assessment for students with disabilities, and online support for the various disability categories to offer students opportunities to succeed.

When there is an unclear policy on decolonization, there have been few strategic and departmental debates about it. As was observed by Higgs (2016), the success of any HE system is based on the curriculum; an inclusive approach needs to be based on a thorough understanding of the indigenous knowledge embedded in it. This requires systematic support through strategic policies and procedures that create the right place for sharing knowledge systems and that are innovative enough to explore the relevant curriculum. One obvious issue was the work overload and that many of them are inclined to pay attention to the basic tasks of teaching and student support while giving insufficient attention to a critical examination of curriculum, content redesigning, and discussions related to curriculum redevelopment. Such policies and guidelines would provide a platform that supports and develops critical and analytical thinking by members of the staff relating to exploring indigenous knowledge to produce contextualized and indigenous curriculum.

Awareness Programs for Staff

One shortcoming identified by this case study was ignorance exhibited by members of staff about disability and, at worst, minimal to no knowledge on how to deal with students with disabilities at various levels during their programs of study. Second, knowledge about decolonization was limited to very few members of staff, which showed a total lack of understanding of both decoloniality and inclusivity. It would be ideal if the current cohort of staff were trained and kept informed about issues of disability and inclusivity. They need to be encouraged to learn more about the decolonization of curriculum and whether their current positions require post-training, research, and innovation support toward decolonization. It might be worthwhile to consider that members of staff who embrace transformation and decolonization initiatives have relatively smaller teaching workloads so that further research and curriculum development initiatives can be driven by such cohorts.

Strategy on Decolonization of Curriculum Inclusively

The university needs to investigate the various ways and forms through which the curriculum is conveyed and imposed on several qualifications. It is important to investigate the content that students are always exposed to (convert colonial curriculum). This would require institutes to pay attention to the content, knowledge pedagogical approaches, and all aspects that are embedded in the ways of knowing. There is also a need to relate decolonization and transformation to internationalization by ensuring that this is in line with global developments aimed at improving the quality of livelihoods of people who consume it. Institutes need to reduce the level of student stigmatization, especially that linked to disability and language, for example, cases, where additional classes offered to improve students in English language and academic writing to place such students at an acceptable academic level, were a reflection of colonial knowledge consumption and perpetuation. Shay (2015) reflects that language and knowledge are synonymous and apart from subjects such as medicine or the sciences. Students can adjust to different contents taught in the home languages as that would constitute an aspect not only of diversity but cultural contextualization so that no one is left behind based on language inadequacies. It is important to identify imperial ideologies and how they shape academic practices. Scott (2015) emphasized that there is no way institutes can create new ways of teaching and learning by reverting to the old way of doing things. Decolonization and inclusion cannot be achieved through old outdated formulas but would require extensive innovation across languages culture, technologies, and content.

Change and Quality Assurance Programs

Several HE Institutes in Africa are tackling decolonization and internationalization of curriculum inclusively. Decolonized teaching does not mean the adoption of compliance-based approaches, which may entail good teaching through a contextualized cultural environment. The university and its departments need to benchmark the existing good evidence and practices from international platforms to identify which work well from an indigenous perspective. This would require reaffirming the cardinal role of staff in promoting and supporting good practices and opportunities and institutional agendas for professional staff development, innovative teaching, and acknowledgment. Such initiatives would undoubtedly lay a foundation for quality assurance measures in curriculum development. It may also be necessary to put quality control processes and measures in place with results, where such information can be shared and peer-reviewed for further improvement of the design of the curricula. As was reflected in the role of students, such a process would take feedback from them to capture how certain courses are matched with students' needs skills and the existing job gaps.

Faculties/Departments and Departmental Support

The chapter observes the role power plays at different institutional and departmental levels. A good staff cohort is the epitome of any successful academic institution. There needs to be coordinated and proper identification of staff who have a better understanding of the internationalization of the curriculum and its pedagogical approaches. Such staff need to be guided by deans who are well-respected academicians and researchers that are bound to lead by example. Further support requirements include a foundation for research excellence that is based on a well-supported and evaluated peer review and promotions process that fosters accountability related to disability-inclusive practices; the initiation of staff innovation award system, especially for high-performing lecturers; and streamlined processes for better governance of the various universities or departments to meet certain diversity targets. Finally, promoting synergies and collaborations among individuals and research units that lay a proper foundation for indigenous curricula need to be encouraged.

A Framework for Decolonization and Inclusivity

The Student Walk model was developed as a would-be user-friendly framework to assist students in finding help within the respective student-related units and sections using a unique seven-step journey. Whereas the Student Walk helps every student to comply with requirements, maximize their UNISA experience, and ultimately succeed at UNISA, we found that it may fail alone in ensuring decoloniality and inclusive access for students with disabilities. The proposed framework (see Fig. 2) accommodates students with disabilities at every step of the way. It pays attention to the overarching context of the institution where students from all backgrounds learn. This inclusive framework suggests that the institutional outlook to inclusiveness from a decolonized perspective would require institutional policies and procedures that drive the goals of the Student Walk model. It also notes that an inclusive approach as well the curriculum needs to accommodate provisions that are decolonized. Such pedagogical approaches could easily break down curriculum content in such a way that no student is left behind. Different curriculum, whether

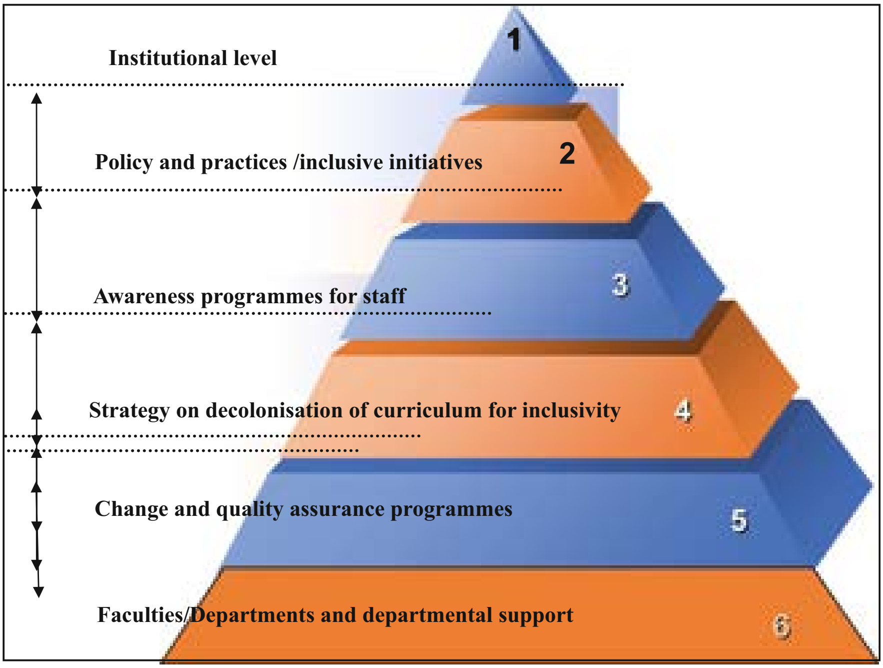

Fig. 2 Proposed pillars of an Inclusive Student Walk

visible or not hidden, may translate into the production of graduates whose outlook regarding employability and lifelong learning is more assured.

For this reason, in the recent HE drive toward internationalization, more prominent consideration has been paid to refreshing and modernizing the educational curriculum to make it increasingly comprehensive of the most recent disciplinary information and aptitudes and progressively intelligent of humanistic qualities (for instance, coordinating multi-culturalism, human rights, and economic improvement into the educational programs). This refocus supports two types of curriculum, the hidden and inclusive. The hidden one alludes to those verifiable lessons adapted casually and even unwittingly through regular social cooperation and the communication with the more extensive organizational culture, statements of faith, and standards. This concealed educational curriculum may likewise impact one's mentalities and attitude on race, ethnicity, sex, sexual orientation, social class, and different variables.

Inclusive practices relate to the hidden curriculum that advances mentalities and acknowledgment of all aspects and barriers to diversity and inclusion among people, especially those with disabilities. This practice is contrary to the common non-comprehensive and concealed educational curricula which may accidentally advance antagonistic generalizations and preference of others dependent on race, ethnicity, gender, sexual orientation, social class, and distinct elements. Actualizing a vision of inclusivity and value involves creating arrangements and projects reliable with that vision and building a long-term strategy that includes required objectives, targets, and assessment and evaluation programs that measure the adequacy of such arrangements. This vision generates reliable institutional policies and regulations not only linked to the overall organizational context but deeply embedded in the strategic plans. Such plans are bound to produce and support decoloniality efforts and showing how inclusive such decoloniality can be.

This implies that decolonising curriculum may not be a pillar alone in the framework but needs to ensure that its content addresses the hidden and unhidden curriculum content through pedagogical means that advocate and support inclusivity at all stages of the Student Walk. Here, inclusive student support programs begin at the institutional context of policies faculty admission of students as it is a well-understood and inclusive process throughout. The framework also advocates for content to be articulated inclusively through relevant pedagogical provisions so that it is accessible to all students regardless of their disability. As an example, special computers for students with visual impairment have to be available to the students from start to end, while their study material would require to be converted to alternative formats, namely, braille, audio, or soft copy so that teaching, learning, and assessment would automatically translate into realistic outcomes – a decolonized and inclusive curriculum.

Conclusion

One of the solutions is to allow the use of inclusion to promote the decolonial movement and to reject the coloniality of expertise, authority, and life in areas of inclusion, by creating a mutually respectful, non-discriminatory atmosphere that promotes diversity and fairness. Studies have shown that students react better when they feel their lecturers' trust in them and that their lecturers reflect less on their weaknesses. HE should also aim for a welcoming community both within the classroom and outside. This is because students are allowed to respect and trust each other, which makes empathy and compassion trendy and encourages learners to support each other with constructive and pro-social attitudes. Efforts and plans should be made by helping others succeed and encouraging progress. This can be done by developing an atmosphere that reflects the diversity of students' interests and by discussing learning that focuses on what students can do and what they would like to do next. Instruction can be provided through tutorials, Individual Learning Plans (ILPs), and setting short- and long-term goals for the students to make them feel they own the learning. If students have chances to tell you what is working, they will have more useful feedback when you make plans. There should be efforts to consider the culture as you learn and teach. Ideals are built by a student's cultural background and their exposure to other perspectives. Invoke the culture to bring the classroom into the inner city. Creating an inclusive environment will not only benefit those students with learning disabilities, but it will also help those students who do not have a learning difference by making them more knowledgeable and accepting of each other.

Students with disabilities and others involved in access issues may continue to be barred from accessing certain professional degrees at the institution if the unseen underlying causes of entry barriers are not evident to them and those involved in access issues. When there is understanding and consciousness that colonialism lies at the root of the barriers faced by immigrants upon arrival, it is only then that these inequitable practices and institutions may be eliminated. As a result, "fixing the underlying cause" would include bringing together all oppressed social groups and non-disabled people who are also resisting oppression to engage in colonialism. In the case of a national intervention, the goal would be to push for a full reform of the tertiary education system as well as complete institutional change to allow all diverse students to obtain professional degrees, learn, and graduate. Graduates with impairments may thus also pursue professional careers and contribute to the development of professional skills for a global, varied market, as would be anticipated in a democratic nation.

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Towards the Integration of Critical Disability Studies in Rehabilitation Sciences Curricula

21

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Abstract

The aim of this chapter is to historicize the status quo of rehabilitation in South Africa and make an argument for Southern Critical Disability Studies to be integrated and embedded in the curricula of rehabilitation sciences (Physiotherapy, Occupational Therapy, Speech Therapy, and Audiology). Three case studies to support the argument anchor the discussion to motivate the logic and demonstrate the mechanics though not exhaustively but with an immensely generative potential in constructive insights for the future of these fields. The central question centers around the productive tension that emerges in a sincere engagement between Critical Disability Studies and Rehabilitation Studies and the implications therein for the overall praxis of rehabilitation sciences. Integrating and embedding critical disability studies that accounts for the hegemonic effects of marginalizing disability as a total social system of oppression may facilitate re-imagining a critical rehabilitation science.

Keywords

CDS · Rehabilitation sciences · Curriculum higher education · South Africa

Introduction

The aim of this chapter is to historicize the status quo of rehabilitation in South Africa and make an argument for Southern Critical Disability Studies (CDS) to be integrated and embedded in the curricula of Rehabilitation Sciences (Physiotherapy, Occupational Therapy, Speech Therapy, and Audiology). Three case studies to support the argument anchor the discussion to motivate the logic and demonstrate the mechanics though not exhaustively but with an immensely generative potential in constructive insights for the future of these fields. The key question centers around the productive tension that emerges in a sincere engagement between CDS and Rehabilitation Studies and the implications therein for the overall praxis of Rehabilitation Sciences. We, the authors, are disability and rehabilitation scholars (three occupational therapists, one audiologist, and one physiotherapist). We are all women of color in the middle-income bracket but with concurrent working class families and other relations. Two of the authors teach and research in the occupational therapy field while three teach and research in Disability Studies across different universities.

The notion of disability is contested within a myriad of theories or models that continuously shape the rehabilitation discourse. These theories serve as defining tools of impairment and inform interventions aimed at dealing with the subject of disability (Ndzwayiba, 2017). The most prominent amongst these include frameworks such as the medical model, the social model, the biopsychological model, and the critical disability lens.

Pothier and Devlin (2006) argued that disability is not fundamentally a medical or health issue nor a phenomenon of sensitivity and compassion but an issue of politics. This reading transcends the liberal social model and posits the normativity and supremacy of able-bodiedness within an oppressive social system that masquerades as a natural state while it limits social and economic opportunities and benefits for those deemed disabled (Barnes & Oliver, 1993; Meekosha & Shuttleworth, 2009). CDS (CDS) emerged from the disability rights movement to challenge the Western medicalization of the lives of persons with disabilities (Grech and Soldatic, 2016; Magasi, 2008). CDS asserts that disability is relational, political, material, and an embodied experience (Garland-Thomson, 2011; Kafer, 2013; Meekosha, 2011). Our understanding of disability echoes Ben-Moshe and Magaña's (2014, p. 105) assertion that "one is always dis/abled in relation to the context in which one is put." By CDS, we also refer to an understanding of disability and impairment in transnational, national, and local contexts as a way of disrupting monolithic discourses of disability in the Global South (Meekosha & Shuttleworth, 2009), while simultaneously opening a platform "to think through, act, resist, relate, communicate, engage with one another against the hybridized forms of oppression and discrimination that so often do not speak singularly of disability" (Goodley, 2013, p. 641). So we advocate for an interrogation of hegemonic Western praxis that will make room for Global South theorization.

We extend Global South perspectives within Disability Studies that remain largely rooted in Eurocentric epistemologies. These Global South critiques advance four moves: (1) the claim of universality that silence realities of persons with disabilities in the south from a different vantage point; (2) centralizing the metropole at the expense of the periphery; (3) grand erasure of the majority of the world's population that lives in the global south; (4) denigration and undervaluing of theory formulated outside of the metropole (Meekosha, 2011).

Black feminist thought proposes use of an intersectionality framework which largely influences CDS scholarship. This framework has also been challenged for positioning disability as an afterthought of race, gender, and class or sometimes an omission (Erevelles, 2011). Broadened discussions on the effects of racialization and colonialism in the Disability Studies scholarship are still needed (Meekosha, 2011). Senier and Barker (2013) argue that even within the vast literature about the health of indigenous peoples' certain impairments (including congenital conditions, mobility impairments, and cognitive differences), the connections to colonialism has not been strongly made. While connection between gender and disability have been made sufficiently (Reed-Sandovala & Sirvent, 2019), it is necessary to probe further when considering the connection between disability and coloniality and the ways which the modern/colonial gender systems reinforce and serve ableism by creating disability and disabled bodies. Specifically, we need more scholarship that accounts for the extent to which coloniality may have created and perpetuate disability itself. The impact of colonialism and imperialism in installing structural violence, disablement, poverty, and inequality for African people in general and persons with disabilities in particular is crucial. To date, our scholarship has not sufficiently addressed the disability–poverty relationship in the Global South and much less connecting it to imperial capitalism.

Within rehabilitation practice, professional areas are also critiqued for their neglect and under-research of the lived experiences of rehabilitation (Shakespeare, 2014). In this chapter, we specifically focus on the core rehabilitation team, namely: physiotherapist (PT), occupational therapist (OT), speech therapist (ST), audiologist, medical orthotist and prosthetist (MOP), and related mid-level workers (MLWs). With mutual benefit between Disability Studies and Rehabilitation Sciences, rehabilitation research remains the preserve of Rehabilitation Sciences and separated from Disability Studies (Shakespeare et al., 2018). Other scholars critique the co-option of Disability Studies language in Rehabilitation Sciences merely for normalizing ends, while not questioning the disabling structures within rehabilitation approaches (Meekosha & Dowse, 2007; Meekosha & Shuttleworth, 2009). Rehabilitation service professionals still treat and discuss disability within a diagnostic perspective, highlighting individual deficiency and still carry controlling and regulatory undertones, even when subsumed under Disability Studies (Meekosha & Shuttleworth, 2009; Leshota, 2013). Oliver and Barnes (2012, p. 42) support this:

> The concept of rehabilitation is laden with normative assumptions clustered around an able-bodied/mind ideal. And, despite its limitations in terms of returning people with acquired impairments such as spinal cord injury, for example, to their former status, it has little or no relevance or meaning for people born with congenital conditions such as blindness or deafness other than to enforce their sense of inadequacy and difference.

Adding on the use of pathology language, Siebers (2013) has similarly critiqued rehabilitation regarding use of simulation activities, as they emphasize a preoccupation with sensations of bodily inadequacy to an extent that participants cannot perceive disability as resulting from social barriers, which is an acute point in CDS.

Historicizing Rehabilitation in South Africa

Owing to its Western orientation as a settler colony, South Africa's public healthcare services have mirrored Eurocentric models where for a long time rehabilitation provision was predominantly institutionalized in individualized bodily impairment therapy (Mji et al., 2013). This biomedical perspective was presented in many definitions of rehabilitation, including the World Health Organization (WHO, 1981) and the United Nations (UN) Standard Rules on the Equalization of Opportunities for Persons with Disabilities (UN, 1993) which subsequently invited many critiques. For example, during the late 1980s, persons with disabilities in South Africa mobilized themselves to challenge rehabilitation professionals to work with the disability rights movement. One of the main criticisms about the medical model of disability was that it places sole responsibility for change upon the individual while paying little attention to barriers that hinder full social integration of persons with disabilities (Chappell & Johannsmeier, 2009). This individualistic focus contributed to the limited recognition of the role of empowerment in the rehabilitation process across fields from health, education, livelihoods, social inclusion, and social justice. The disability rights movement shaped the shifts in the way disability was constructed, thus distinguishing between impairment and disability (Rule et al., 2006; Mji et al., 2013).

The alliances between persons with disabilities and rehabilitation professionals in the 1980s in support of Community Based Rehabilitation (CBR) was also a significant turning point for rehabilitation (Rule, 2008), which promoted and extended the disability rights movement and ultimately mobilized persons with disabilities and their families to re-shape rehabilitation practice. CBR, as developed by WHO in 1984, also focused on impairments in the training of village health workers initially. The 2010 CBR Guidelines expanded the approach from rehabilitation to include poverty reduction and social inclusion (WHO, 2010). Again, a crucial paradigm shift here was a move from conceptualizing CBR as purely a rehabilitation and health-orientated strategy located in the community, to a disability-inclusive development strategy that could have an impact on implementation, training, and policy (Deepak et al., 2011; M'kumbuzi and Myezwa, 2016; Rule et al., 2008; Rule, 2013; Wickenden et al., 2012; Morris et al., 2019; Rule et al., 2019). While it is often misunderstood as referring only to services provided outside of institutions, CBR is a general community development strategy aiming at the inclusion and full participation of persons with disabilities in all aspects of community life (WHO, 2010). Noteworthy is the mutuality of core principles with comprehensive primary health care (PHC), including accessibility, affordability, acceptability, self-determination, empowerment, and intersectoral collaboration (Sherry, 2014). However, the continued reluctance in comprehensively implementing and supporting CBR has not only undermined these alliances, but also raised questions about whether rehabilitation continues to reinforce individualization of disability and institutionalized solutions.

With the advent of democratic governance in South Africa in 1994, policy changes were made. A White Paper on the Transformation of the Health System in SA was developed in 1996 and enshrining the outlawing of discrimination on the grounds of disability. However, recognition of rehabilitation was still generally poor in healthcare as it was overlooked as a component of PHC and not integrated into vertical health programs. This oversight was evident from the poor inclusion of rehabilitation in the PHC package for SA: a set of norms and standards (2000/2001), and the resultant limited budgets for rehabilitation. In 2000, the National Rehabilitation Policy (NRP) (National Department of Health, 2000) acknowledged this oversight and ensured that budgets are allocated towards rehabilitation for each province in SA.

Later, both the WHO (2011) and the UN's Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006), broadly defined rehabilitation as a set of measures that enable individuals with disabilities to achieve and maintain optimal functioning in interaction with their environments. South Africa signed and ratified the CRPD in 2007 and 2008. Since ratification, South Africa also domesticated it through the White Paper on the Rights of Persons with Disabilities (Department of Social Development, 2015). In 2016, the Framework for Disability and Rehabilitation Strategy (Department of Health, 2016) was published with an aim to integrate disability and rehabilitation services within priority healthcare programs at all levels of the health system (from primary to specialized care) and through coordinated action across sectors. It also advocated for comprehensive services across the lifespan. However, the policy lacked provincial implementation guidelines and there has not been provision of such services to date. While the White Paper on the National Health Insurance (NHI) (Department of Health, 2015) acknowledges rehabilitative care as included in the PHC continuum, there are currently no integrated rehabilitation indicators. These shifts have reshaped not only rehabilitation practice but also the education and training of these professionals in order to produce the required graduate competencies. In all these shifts, we see a picture where rehabilitation continues to occupy the margins. Even in discussions about interprofessional health teams, rehabilitation is often excluded and reference is only made to other medical teams (see Volmink, 2018).

While CDS has offered both a critique of rehabilitation and an opportunity to improve practice, it is not clear how rehabilitation education has been mindful of such critiques. Despite these policies, disability remains an afterthought and the transformative issues raised by persons with disabilities and the disability rights movement remain ignored. The policies similarly have not transcended the preoccupation with binary conceptualizations of disability that CDS has long criticized. These limitations have been recognized in the struggles to implement CBR practice and rehabilitation remains focused within the health sector only. Likewise, the commonly used International Classification of Functioning Disability and Health (ICF) (WHO, 2001) in the health sector is particularly critiqued for reproducing the Western discourse of normal/abnormal binary and maintains that abnormality is deviant and in need of intervention at biomedical level (Mosleh, 2019). For instance, Mosleh (2019, p. 9) argues:

> ...the ICF's acknowledgment of the social mediators of disability does not preclude its reliance on the discourse of normal/abnormal. Indeed, my analysis has rendered visible the multiple ways in which an understanding of dysfunction predicated by statistical norms, and a bio-reductionist understanding of impairment perpetuate an understanding of impairment as objectively defective prior to its measurement. These ideas are pervasive and extend beyond the ICF and rehabilitation, and influence how disability is understood in social contexts. The normal/abnormal, abled/disabled dichotomy is a prevalent social "truth," which has a long history and holds severe implications for the way in which persons with disabilities are understood.

Mosleh concludes that the ICF re-inscribes the abled/disabled dichotomy in ways that privilege "abled bodies" while devaluing disabled bodies. Additionally, Mosleh suggests that resolving these tensions may offer unique opportunities to negotiate and prioritize what really matters when working with and for persons with disabilities.

We posit that it is crucial for rehabilitation education to impart a CDS perspective in order to produce practitioners who are open to changing the status quo, instead of maintaining it. We hold the view that rehabilitation education must respond to CDS critiques in order to make itself more responsive, more relevant, and more empowering to persons with disabilities in the Global South, through challenging disabling systems, social structures, and the ongoing marginalization and devaluation of people with disabilities (Magasi, 2008; Kielhofner, 2005). It is here that rehabilitation could also shift from being perceived as practice "done to" rather than "done with" the collaboration of people with disabilities. These developments guide the perspectives described in this chapter.

Southern CDS and Rehabilitation Sciences Curricula: The Shortcomings

Building from the theoretical case made earlier for Global South theorization, Nguyen (2018, p. 5) asks: "Why do we need to engage Southern theory?" For us as disability and rehabilitation educators located in the South, this question is important because it begs another question about discursive knowledge production in Disability Studies. As intimated, knowledge production has historically privileged the Global North (Meekosha, 2011; Nguyen, 2018) so this question is an opening and a call for Global South epistemologies. While Disability Studies transcended disciplinary borders, the most authoritative representations of persons with disabilities still arise from therapeutic- or medical-related disciplines. The crucial role that Higher Education plays in preparing graduates to be agents of change in rehabilitation practice cannot be over emphasized. Alsop et al. (2006) argue that traditional approaches to health professions education (inclusive of Rehabilitation Sciences), with its exclusive focus on biomedical knowledge, were not adequate to develop graduate competencies required for community-based rehabilitation (recently advocated for as community based Inclusive Development). The same can be argued for shaping rehabilitation practice that embodies CDS. Building on Nguyen's question above, are we engaging indigenous ways of knowing about disability in our curricula and interrogating the dominant western theory? How does this shape practice in the South?

Rehabilitation Sciences curricula should produce relevant rehabilitation professionals who are not only clinically competent but who also critically engage with the contexts and histories in which they practice. In the context of disability, critical engagement implies that rehabilitation professionals are able to respond to issues of diversity, equity and inclusion to achieve social justice as these issues cannot be separated from the lived experience of disability. Luckett and Shay (2017) assert that curriculum renewal is one means of challenging and dismantling injustices and inequalities in society, if power dynamics are addressed explicitly in the curricula. They suggest that a transformative approach to curriculum could consciously address questions of difference and power in society. This transformative approach speaks to a different kind of Rehabilitation Sciences curriculum. Literature on a decolonial approach to higher education (Ramugondo, 2018) as well as Freire's concepts on reflexivity and critical consciousness (Freire, 1990) provide a lens for thinking about Rehabilitation Sciences curricula that would deliver practitioners who provide relevant services to a diverse population and who are also competent as disability activists in the contexts within which they practice.

Re-framing Rehabilitation Sciences Curricula Within Southern CDS

In the following sections, we present and draw on three case studies to frame our position around curriculum re-design and integration of CDS in Rehabilitation Sciences education. In an attempt to improve a curriculum, improvement of rehabilitation curricula inclusive of CDS is important and the following cases are in service of that argument.

Case 1: A Case of Annie D: The Humble Servant

Professional role transgression is conceptualized as a means by which individuals enact professional agency within hegemonic structures (Sonday et al., 2019). It is considered as a form of occupational consciousness which refers to "the ongoing awareness of the dynamics of hegemony and recognises that dominant practices are sustained through what people do every day, with implications for personal and collective health" (Ramugondo, 2015, p. 488). The case of Annie D stems from a doctoral study (Sonday, 2016) that describes how occupational therapists navigated their professional role transitions along a trajectory in time, post-apartheid. Annie D's role as an occupational therapist within the specialized education sector was seemingly clear as she pursued a career at a special school for children with disabilities. However, role clarity became blurred as events unfolded that forced Annie D to continuously reposition herself. The ratification of the Employment of Educator Act of 1997 called for all therapists working at schools, to be called education therapists. The fear of what occupational therapists were going to become felt like a loss of professional identity. Annie D referred to herself as the humble servant. She graduated in March 2001, with all her hopes and dreams on the verge of becoming a reality. She made the shift from working in the health to the education sector. This shift was motivated by greater positive prospects. However, this was not the case for Annie D. There was a disparity between the interview expectations with job reality. The biggest perception that was taught to her during her training years was that an occupational therapist could offer many roles at a school. The aim of employing other occupational therapists was to improve on the intervention outcomes for school children. Practice was meant to shift from an individual to group and population focus that could potentially extend beyond the school. These ideas really excited Annie D. She was promised an outlined job description with roles and duties which come to pass. In reality, the school had no such documentation and the role was controlled whimsically by the management, made up of the principal and the foundation phase teachers with no fellow therapists. There were two occupational therapists at the school under the supervision of a deputy principal with limited understanding of occupational therapy's potential. For Annie D, it felt like a militaristic command chain where she was forced comply to orders with no alternatives. As time progressed, Annie D searched for alternative work.

She realized that the role context determined, she had customized to that. She became aware that the school management type determined one's place in the system. At the time, she did not realize the erosion it had caused at her professional identity as an occupational therapist:

I started adapting to the school environment in my second year. When you start adapting, that environment becomes the norm, and that is scary. I started feeling as if my wings had been clipped. I felt like a puppet on a string. My mind was telling me to do the right thing, but my body was being controlled by a management system at the school that I had no control over.

There were many contextual factors that contributed to Annie D's struggle. First, the immediate schooling environment limited freedom of expression and thus severely impacting the value of an occupational therapist where participating in decision-making is critical:

As a therapist you are isolated and the lack of structure contributes to this sense of isolation. I think that if I were offered more support, things would be different. I really did not function well in this school environment, which explains why I ended up getting admitted to a clinic.

Second, patriarchal decision-making hierarchy controlled and selectively filtered information down to the therapists, a fundamental breaking point for Annie D.

I've come to the realization that the management at the school is limiting our role as occupational therapists and our scope of practice. They are not giving us the scope to take on different roles. For example, we can play a role in contributing to management decisions regarding therapy services for the learners. But our role is not only restricted within the four walls of the school, our role extends beyond here and into the community. As occupational therapists, we have a background and knowledge on normal development and barriers to learning, which we can share with teachers and other staff members in the form of a workshop, but these opportunities are not granted to us.

Third, there was no leadership opportunities for growth and professional development at the school. The autocratic governance expunged the scope for new ideas of practice:

The school is 25 years old and the play area is still not established. Along with the occupation of schooling, play is one of the main occupations of a child. But, you see, upgrading this part of the school is not seen as a priority because occupational therapy is not valued. So why would they value a play space? Sometimes I feel that we're just there because we are there. So, act like you are doing something because it's okay as long as they see you working with people. I battle with understanding how pretending to be effective is ethical practice? There is this vision of justice and working together, but it's not the reality. There is a breakdown in teamwork and it's got nothing to do with occupational therapy, unfortunately, it's on the management side. That makes it difficult. There is potential for occupational therapists to offer more, but we are prohibited by so many factors.

These factors point to Annie D's struggle with adaptation and role fulfillment in working with children with disabilities. Some questions for reflection:

If the knowledge and skills in negotiating the interplay between structure, professional identity and professional agency was included and taught in her undergraduate training, would Annie D have responded differently?

What critical elements related to professional identity development should have been foregrounded in her training that could have better prepared her?

Case 2: Re-designing a Curriculum for Disability Inclusion in Occupational Therapy

The influence of a critical curriculum are exhibited by its graduates through their own empowerment beyond the confines of the university (Freire, 1990). Uncovering graduates' practice could illuminate developments in the curriculum that may be required to address critical competencies. This second case is based on a descriptive case study that involved seven novice occupational therapy graduates from the University of the Western Cape (UWC), Cape Town, South Africa (Hess-April, 2013). An overview of the graduates' practice experiences within PHC services in the Eastern Cape, Northern Cape, and Western Cape provinces was generated through participant observation, semi-structured interviews, and document review. The general practice contexts of the occupational therapy graduates were rural and characterized by poverty, thereby a high prevalence of inadequate access to disability health services. Occupational therapy services were predominantly individualized within a clinical, reductionistic approach. Most persons with disabilities in PHC clinics wanted to apply for a disability grant as a means for income as jobs for persons with disabilities were scarce due to employer discrimination, even amongst those encouraged to search for work. This limited view meant few people accessed occupational therapy services with disparities in population and disability profile. Travel costs and transport inaccessibility also meant a lower turn out not for occupational therapists but other rehabilitation professionals as well.

The biomedical approach dominated the graduates' practice with resources mainly dedicated to curative services provision with little attention to community integration for people with disabilities. The medical model of disability, which sees disability as individualized and draws attention away from the oppression of persons with disabilities societally, neglecting the role of activism around disability rights and inclusion. Some graduates demonstrated advocacy and inter-sectoral collaboration to network for opportunities for people with disabilities to sustain their livelihoods and to access resources available to them. Practice involving disability inclusive development were minimal and the graduates were not effective in establishing strategic collaborations to address meaningful change; even if they managed to establish such partnerships, their managers and the provincial Departments of Health gave no recognition of it as part of their role. Similarly, while the graduates appeared to be critical about unavailable resources or policy implementation to address disability inclusion, they did not engage in actions to address these issues, resulting to an unchanged practices around disability inclusive development.

In assessing the extent of the graduates' competencies towards fulfilling disability inclusion, political proficiency and critical reflexivity on issues of diversity, inclusion and justice would be useful. This consideration then raised several questions:

- What form of reflection was being facilitated in the curriculum?
- Was it oriented towards analytical reflection rather than critical reflexivity examining both personal and professional values?
- Does reflection move beyond the individual level to include a critical perspective that takes into account issues of power leading to change actions to address these?

Subsequently, the need for the integration of a CDS component into the UWC occupational therapy undergraduate curriculum became clear. Informed by critical disability perspectives, the curriculum was re-designed to enable students to question and challenge their own and others' attitudes, beliefs, and actions around disability. The implication was the adoption of critical pedagogy (Freire, 1990) and transformational learning (Mezirow, 1997) as a teaching and learning approach. Through active dialogue and Freire's problem-posing methods, educators actively challenge traditional constructions of disability, thereby disrupting students' attitudes towards people with disabilities. This facilitation is done from the position that occupational therapy education must challenge systemic issues that perpetuate marginalizing practices and thus influence historical perspectives on rehabilitation. In addition, the curriculum facilitates understanding of international and national policies for disability and rehabilitation and how these policies inform practice for advocacy and enhancing disability inclusion through CBR/disability inclusive development. A key learning outcome is the development of students' capacity for questioning and challenging the status quo concerning people with disabilities. The following extract from a student's reflective journal on the integrated redesigned curriculum testifies:

When we were children, my mother taught me to help those in need and be grateful for what I have, and in many aspects of life I am immensely grateful for the lesson. However, from these lessons rooted a certain perspective or prejudice towards people with disabilities. Whenever we came across people with disabilities my mother would say something like "shame," and tell us to be grateful for our healthy bodies, followed by a slight scolding for staring too long. My grandmother did the same, and so did her mother.

I realized that in my years of study, I had been implementing the charity model of disability. In retrospect I observed that I had been taking what my mother taught me as kindness, empathy, and twisted it into the very thing that is perpetuating the problem. Although I often concentrated on the strengths of the clients rather than their disabilities, I found that I always saw their disability first, and then immediately saw them as patients. I was reducing them to their problem, and I was separating them based on pity.

Although I was initially weary of the word privilege, which rooted from my lack of understanding, I was refusing to admit that my own identity as a person without a disability was the root of the pity that I demonstrated. My prejudice as a therapist may be even more damaging than that of the rest of society.

The knowledge I have acquired over the past 4 years also came with its own risk and responsibility. Even as a student and future occupational therapist institutions and systems grant me a certain level of "power." However, in the hands of people who have the wrong perspective on people with disabilities, this may lead to power mechanisms that may oppress and reduce the clients to passive recipients of care.

I realized; before I can advocate for inclusion and fulfil my responsibility as an occupational therapist, I need to critically examine and rectify my own practices that are perpetuating oppression. I thought I was advocating for inclusion when in reality I was advocating for mere integration. I wondered if this may not be happening with many other therapists. The question arose for me, how can we make society self-reflect? How can we make society question their own behavior?

Through the adoption of critical learning and teaching approaches as explained above, students re-examined their understanding and approach to disability. Rather than uncritically adopting a deficit-model approach, they began to challenge oppressive practices that traditionally influence occupational therapy practice as illustrated in the quote.

Some reflective questions to consider:

1. To what extent does education equip rehabilitation professionals to counter hegemonic pressures exerted on them?
2. How can the curriculum facilitate competencies to engage in relevant practice actions for disability inclusion?

Case 3: Training a New Cadre of Community-Based Workers: Interdisciplinary Collaboration in the Higher Certificate in Disability Practice (HCDP)

The focus of this case is on the Higher Certificate in Disability Practice (HCDP). Grounded in the ideological intention of a socially just curriculum, the HCDP facilitates the delivery of equitable healthcare to people with disabilities at community level. It furthermore encourages rehabilitation professionals to work in an inclusive and interprofessional manner (Gamiet & Rowe, 2019). The HCDP program seeks to include and address national and global trends in education (Hartman et al., 2012) and health with a focus on Interprofessional Education and Collaborative Practice (IPECP), PHC and CBR. This program is within the Division of Disability Studies in the Department of Health and Rehabilitation Sciences at the

University of Cape Town, South Africa, and sets out to achieve the outcome of affirming, advocating and accounting critical disability priorities across sectors. The Division of Disability Studies is interdisciplinary and emerged from a need for disability activists from various organizations such as Disabled People South Africa (DPSA) to have a qualification as well as the need for disability inclusion across academic spaces and the need to develop disability-inclusive research capacity in South Africa. Through its interdisciplinary academic programs, the Division has a multi-pronged approach in achieving this outcome. The programs offered are a Higher Certificate in Disability Practice (HCDP), a Postgraduate Diploma, Masters of Philosophy and a Doctorate of Philosophy in Disability Studies. Disability Studies alumni are able to make an impact, at the level of higher education curricular change, service delivery, community advocacy, policy, and planning. This impact is achieved through their work in community, non-governmental, governmental, higher education and private sector entities where alumni have an influence and voice.

The pilot of the HCDP was done collaboratively through an initiative of the Western Cape Department of Health, who funded the curriculum design and implementation of the pilot of HCDP program in 2012. Two universities collaborated with the Division namely, the Department of Physiotherapy and Interdisciplinary Unit in School of Public Health at the University of Western Cape, and the Centre of Disability and Rehabilitation Studies and Department of Community Health at Stellenbosch University. The HCDP qualification responds to the policy on re-engineering PHC in South Africa, which necessitated the development of human resource capacity, particularly in the field of rehabilitation and disability services, which is under-resourced, and not meeting the needs of persons with disabilities and their families (Department of Health, 2016).

The HCDP curriculum is innovative by its educational design and in its delivery. Multiple elements of curriculum design, which included content, teaching and learning activities, assessment practices, the ideological approach (McKimm, 2007), were considered and carefully mapped out by relevant stakeholders.

The pedagogical approach used in the HCDP involves a focus on interprofessional teaching. The teaching team includes persons with disabilities, social workers, audiologists, occupational therapists, speech therapists, physiotherapists and community rehabilitation workers. In order to deliver the curriculum in an interprofessional way, the facilitators have to model interprofessional practice by stepping out of their professional silos. The intention was to make explicit to students and therapists how interprofessional collaborative practice might be applied in service delivery when working with persons with disabilities, families and communities. Action learning (Freire, 2016) was intentionally used as an approach to reciprocal learning with more traditional didactic teaching methods. In using an action learning approach students were given the opportunity to experientially engage in activities and practicals in class, reflect on these learnings and apply it in future teaching and learning spaces. A cognitive developmental approach is adopted in the teaching and learning spaces (Toohey, 1999; Biggs, 2012). It is important for graduates to be critical thinkers and reflect-in and -on action (Schonn, 1987) in order to collaborate in problem solving. During the Work Integrated Practice Learning courses, HCDP students were afforded the opportunity to practically work closely with various health care professionals and community development practitioners across a variety of contexts in order to understand the value and purpose of interprofessional collaborative practice.

In order to transform rehabilitation at community level, the HCDP qualification supports the National Department of Health's human resource plan to have community rehabilitation workers as part of the PHC team to address disability and rehabilitation needs in communities (Department of Health, 2015). The curriculum aims to capacitate graduates with integrated rehabilitation skills to access information, to communicate with families, communities and the PHC teams, as well as to support services and programs for persons with disabilities and their families. HCDP graduates have a generic set of clinical skills to screen and identify persons with disabilities. They implement an intervention designed/developed by therapists related to addressing individuals' impairments, remove barriers to participation and inclusion and create spaces for persons with disabilities to empower themselves.

The graduate can play a key role in the PHC platform, contributing to the promotion of health, prevention of disease, access to the provision of assistive devices and technology and augmenting rehabilitation services at community level. The HCDP graduate can also play a key role in community and social inclusion. Their role facilitates the reintegration and inclusion of persons with disabilities into communities so that they are able to participate and are included in spaces of living, work, learning, playing and socializing. However, challenges for this cadre of community based worker both within the level of training and at the level of service delivery still remain.

At the level of training, interprofessional education across all cadres of Rehabilitation Sciences remains challenging due to administrative, logistical concerns and the protection of professional identities. Within the training model, a shift in ways of being and thinking is required. Undergraduate training programs in Rehabilitation Sciences such as physiotherapy, occupational therapy, and communication sciences could consider introducing a CDS approach in their curriculum planning and design. There is potential for all these undergraduate professional qualifications to train their students, including this new community worker, on CDS in an interprofessional way. CDS will lay the grounds for disability inclusive practice and collaboration amongst students of all Rehabilitation Sciences. In addition, it would be beneficial if the therapy students are provided with experiential learning opportunities to work more closely and collaboratively with the HCDP students and graduates at practice learning placements. This collaborative practice will not only afford them an opportunity to understand and value the role that each rehabilitation practitioner plays within the system; it will also foster an understanding of how each profession needs to work together to ensure that inclusion of Persons with Disabilities is prioritized.

As educators of rehabilitation professionals we need to reflect on what underpins our training. When drawing on Kaplan's (1999) elements of organizational capacity development, we need to redefine our conceptual frameworks to include critical disabilities studies at the core, and then accordingly adjust the organizational values, vision and mission and our approach to drive the training and acquisition of skills. The CDS theory and CBR guidelines are useful frameworks to guide learning and position CDS as a theoretical underpinning in rehabilitation curricula. Currently frameworks and professional ways of being remain that are negatively influencing our ways of practicing and service delivery.

At the level of service delivery, there remains an uncertainty about the role of the community rehabilitation worker and how and where they fit into the healthcare system. Concerns about a potential threat of the community rehabilitation worker to the employment opportunities of other rehabilitation professionals was noted. Challenges around the responsibility of rehabilitation therapists in relation to the supervision of the community rehabilitation worker also created uncertainty. This cadre of community based worker is recognized as an important new human resource in Africa (Dawad & Jobson, 2011) as well as locally within the Western Cape Department of Health's 2030 Healthcare plan (Western Cape Government Health, 2014). The challenge with professional regulation of the community rehabilitation worker has the potential to limit service delivery. Regulating their scope of practice is often complicated by power dynamics between and within these professional regulatory bodies. This professional regulation may further be complicated because their scope of practice is integrated and includes skills and roles from different rehabilitation professionals. Adequate remuneration, finances, resources and ongoing professional development needs to be allocated to establish their integration into the service delivery platform (Booyens et al., 2015).

Some reflective questions to consider:

- What pedagogies can we use to embed CDS as a conceptual framework in Rehabilitation Sciences education and curricula and
- How can CDS drive the necessary interprofessional education and collaborative practice in the teaching and learning spaces in Rehabilitation Sciences curricula?
- How do we extend our engagement beyond formal educational spaces to dismantle systems and structures that uphold professional sectarianism and asymmetrical power relations?
- On a service delivery platform, how do we integrate this cadre of worker into the rehabilitation team to facilitate collaborative practice and strengthen PHC and CBR?
- How can educators of health and rehabilitation professionals become change agents to drive instructional, institutional and systemic transformation?

Discussion: Imperatives of Southern CDS for Rehabilitation Sciences Curricula

It is a mandate of higher education institutions (HEIs) to develop programs that influence social change and address challenges facing disadvantaged members of society. The three cases above demonstrate that curricula transformation is required, if we are to produce graduates who are agents of change in their respective contexts.

To prepare these graduates adequately to facilitate critical disability work in its full complexity, notions of curriculum design and pedagogy within Rehabilitation Sciences must be re-examined. Kaplan (2000) provides three tangible and three intangible elements for organizational capacity. Tangible elements focus on elements that are quantifiable are on their own not effective in building organizational capacity. Intangible elements largely determine the way in which an organization achieves what it sets out to do.

In the following section, we intentionally use only the three intangible elements of Kaplan's framework, i.e., conceptual framework, organizational attitude; and vision and strategy, to provide a critical analysis of the capacity of higher education to facilitate an integration of southern CDS into Rehabilitation Sciences curricula in light of issues raised by the three case studies. We highlight gaps and opportunities that exist in Rehabilitation Sciences curricula as well as consider implications for the integration of a southern CDS.

Conceptual Framework – Reconceptualizing Disability and Rehabilitation Within Rehabilitation Sciences

In recent years, there has been a shift towards education programs in Rehabilitation Sciences becoming socially responsive thus alerting to a conceptual framework that reverences the right to equality and equitable access to opportunities for persons with disabilities. In order for the Rehabilitation Sciences curriculum to effectively facilitate the development of practitioner competencies to facilitate the community integration of persons with disabilities in practice, there must be a shared conceptual framework and understanding of disability that is holistic, that views disability as an issue of social justice and that takes intersecting identities into account. Unless all educators share an appreciation for the complexity of the disability experience and the embodiment of disability (Siebers, 2013), and free themselves from the doctrines of the medical model (i.e. an individual impairment focused approach to disability inclusion), health sciences education will not fully comprehend and intervene into issues of disability exclusion. Sieber's (2013) theory of complex embodiment calls for neither a prioritization of the medical or social model, but rather for the complexity of disability to be recognized. The theory of complex embodiment also enables the understanding of a disability identity amongst other identities as an epistemological construction containing an array of theories about navigating the social context. The body and social representations are mutually transformative and intersecting identities such as race, gender, socioeconomic status, education, religion, sexuality interact or overlap, contributing to multiple layers of possible vulnerable identities and social oppression.

Organizational Attitude: The Importance of Critical Reflexivity and Agency in Affecting Social Change

In Case Two, the practice of novice occupational therapy graduates illuminated that they seemed to view disability as primarily related to loss of function rather than as a form of social oppression. This assumption is not surprising, as Rehabilitation Sciences traditionally understood disability within a reductionist perspective that emphasizes individual impairment. This perspective has clear consequences for education and practice. While not directly implied in Case One, a reading of the case poses questions on how disability is conceptualized in the special school setting. However, Case Two does also illustrate how the curriculum, informed by CDS, undertook to enable students to question and challenge their own and others' attitudes, beliefs, and actions around disability. Adopting CDS perspectives allows for the recognition and confrontation of harmful systemic representations of disability. A core premise of CDS is that it challenges the view of disability as an individual deficit that "experts" such as occupational therapists can remedy through medical rehabilitation. Taking a critical reflexive stance can bring change through action. As illustrated in Case Two, students could re-examine their implicit biases and begin to challenge oppressive practices that traditionally influenced rehabilitation.

Freire (1990) stresses the importance of allowing students to recognize connections between individuals and the broader social contexts in which their experiences are embedded, through the deconstruction of power relations. Case Two highlights how integration of CDS in a curriculum could develop critical graduates through facilitating reflexivity that enables them to interrogate their own values addressing questions such as:

- How do my own value systems influence my practice?
- How might my practice change as a result of reflections on my value systems?
- How do different forms of power in my practice context influence my practice?
- What processes could I use to challenge different forms of power?

At the center of an organization's ability to effectively deal with issues pertaining to disability and social inclusion/exclusion, lies how it understands and interprets the construct of disability. As highlighted by the above discussion, both Case One and Two illustrate some success in influencing an occupational therapy student's perception of disability through the introduction of critical reflexivity around theorizing of disability in the curriculum. The value of critical reflexivity for Rehabilitation Sciences educators around these questions should not be underestimated and could provide momentum to a transformation on how health professions education views disability and rehabilitation and the adoption of CDS as a conceptual framework for the curriculum.

Vision and Strategy: A Transformative Rehabilitation Sciences Curriculum as a Change Agent Within Itself Through CDS

CDS perspectives underline that disability is currently dominated by medical knowledge and power. Adopting CDS perspectives allows for the recognition and confrontation of harmful systemic representations of disability. Currently traditional rehabilitation perspectives on disability receive more attention in Rehabilitation Sciences curricula, portraying an organizational attitude of cultural privilege that is ignorant of the important role of critical activism where rehabilitation professionals could collaborate with the disability rights movement around disability rights and inclusion.

CDS contributes substantially to the examination of political strategies of intervention that can confront barriers to social inclusion. While Case Two provides an example of facilitating this much needed shift on transcending the impairment focus in order to deliver holistic rehabilitation services, Case Three challenges notions of invisibility by bringing in persons with disabilities not only as students or recipients of rehabilitations but as lecturers in the program. These critical shifts address/highlight the hegemonic medicalization of disability that has contributed hugely in making disabled bodies invisible and in perpetuating dehumanizing ways of thinking about disabled populations (Reed-Sandoval & Sirvent, 2019).

Case Two illuminated novice occupational therapy graduates' inability to engage with disability as an issue of difference and highlighted the need for curricula to equip students with skills to work collaboratively. Julio, Chen, Bhutta, Cohen, and Crisp et al. (2010) advocate that engaging stakeholders is crucial to ensure that partnerships reflect mutually negotiated objectives and community needs. They call on education programs to form networks and alliances with relevant stakeholders in order to harness educational content and teaching resources. The inclusion of persons with disabilities in curriculum development as well as teaching and learning is imperative (as Case Three highlights) to foster values of inclusion as part of the educational environment. An important principle for education is that it reflects valuing the lived experiences of persons with disabilities and learning from, and working in, partnership with disability networks and organizations in offering health-related rehabilitation, as well as advocacy campaigns and disability inclusive development programs. However, Rehabilitation Sciences departments at higher education institutions need to put in the work required for the questioning of coloniality and the colonial/modern system's reinforcement of ableism; and the creation of disabled bodies and disability.

Most importantly, any decolonial work requires prioritizing voices of the oppressed. This mandate demands Rehabilitation Sciences engage Reed-Sandoval and Sirvent (2019, pp. 1553–1554) questions of "who gets to define ability and disability in a given context" and "how disabled bodies and spaces serve as sites for producing theory, knowledge, and philosophy and the historical and colonial formations and manifestations of the ability-disability distinction." For instance, due to a largely colonial way of providing education (Ned, 2019), we have not adequately accounted (in policy, theory and practice) for African indigenous approaches to understanding and dealing with disability. This absence / gap is because curricula have generally focused on Western ways of knowing and being, which reinforces epistemic vulnerability of disabled population, particularly those from the periphery. There is limited conceptualization of disability from the frames of reference of those in the periphery. Considerations of how indigenous approaches to disability would influence rehabilitation practice must be explored. There must be transformative actions implemented to undo past practices, informed by engaging questions such as:

- Who is the ideal knower regarding disability in rehabilitation disciplines?
- How can persons with disabilities themselves become part of academic practice?
- What practices need to change and how?

Given that even CDS' theorizing and critiques have largely ignored indigenous people (Driskill, 2010), care must be taken not to perpetuate this exclusion of indigeneity through ignoring political factors that caused the inequalities and the dominance of the global North and unthinkingly adopting these cultural values and beliefs in the Global South. Case in point are minimum standards for Rehabilitation Sciences education that are set by World Professional Bodies that do not consider Global South contexts. A transformation of organizational attitude implies the Rehabilitation Sciences curriculum transforming to the extent that it becomes a change agent within itself in how it responds to the world around it, through adopting CDS as a conceptual framework in which Rehabilitation Sciences curricula.

Vision and Strategy: CBR as Tenet of a Transformative Rehabilitation Sciences Curriculum

Health sciences curricula generally do not portray a clear vision and strategy for rehabilitation services or for developing relevant practitioner competencies to deliver such services (Volmink, 2018). As illustrated in the three case stories, there appears to be different approaches adopted within different programs. A clearer vision and strategy foregrounding CDS must be exhibited within the tenets of the curriculum, outlining priority areas for practice, particularly as related to community integration and disability inclusion.

A CDS curriculum implies preparedness of practitioners to engage in a critical practice of rehabilitation as encompassed in the CBR Guidelines (WHO, 2010), where rehabilitation refers not only to the components of health but also of the social, education, and livelihood which are underpinned by the empowerment, to achieve disability inclusive development. CBR, itself, is seen as an effective strategy for promoting disability rights and to operationalize the CRPD through equaling opportunities for development. These components have nonetheless been neglected in rehabilitation shown in the disconnect between CDS and practice (Hess-April, 2013; Ned & Lorenzo, 2016). This neglect highlights an imperative for Rehabilitation Sciences curricula namely interprofessional education and collaborative practice (IPECP).

Frenk et al. (2010) highlight that educational instructional and institutional reform is required to promote and drive interprofessional education for Health professions. They argue that fostering interdependence in interprofessional learning has the potential to dismantle professional silos and hierarchical relationships. This dismantling is a necessary iterative process between education and practice required to train competent graduates committed to disability inclusion through participation (Frenk et al., 2010; Barr, 2011). Barr (2000, p. 6) asserts that interprofessional education provides opportunities to develop "productive learning relationships" between students. The experience of this model of collaborative practice during training facilitates opportunities for replication in practice upon qualification. Volmink (2018) support this model as he credits IPECP as a catalyst for transformation. In addition to transformative learning being reciprocal between students and educators in ways that alters power dynamics and creates critical reflexivity (Freire, 1990), learning to collaborate in a transformative way can be achieved by facilitating teamwork and collaboration between students in educational spaces. However, barriers to IPECP are still rife in Rehabilitation Sciences' education and practice.

Barriers include hierarchical and power dynamics and administrative logistical challenges (e.g., coordinating schedules). Such a situation continues to perpetuate inadequate delivery of rehabilitation services. These barriers are compounded by findings that rehabilitation remains on the margins in public healthcare (Sherry, 2014) and limited as a cross-sectoral practice (Ned et al., 2020). Dufour and Lucy (2010) highlights the need for a "paradigm shift" that goes beyond a diverse health care team to include other stakeholders in other sectors. An example here is Case One that shows an OT in a special school that is within the education sector. We argue that for a paradigm shift to be implemented, it must start with training with transdisciplinarity. We submit that higher education institutions' embrace integrated and embedded service learning programs for rehabilitation science students by facilitating opportunities for students collaboration stakeholders across sectors including persons with disabilities organizations.

The implications of holding on to the four disciplines of occupational therapy, physiotherapy, speech and language therapy, and audiology are seen in Case Three where collaboration yields interprofessional co-valuing of each professional in the rehabilitation service chain even beyond the health sector given rehabilitation's expansive reach.

While Case One acknowledges having to deal with restrictive governance models, the effect of professional identity erosion affects change agency. Volmink (2018) argues that "professional tribalism" is another important barrier to effective collaborative practice and transformative change in healthcare. Attitudes of practitioners lead to hierarchical classifications that need to be addressed (Snyman et al., 2015).

Gordon (2006), calls for disciplinary decadence which he defines as:

the phenomenon of turning away from living thought, which engages reality and recognizes its own limitations, to a deontologized or absolute conception of disciplinary life. The discipline becomes, in solipsistic fashion, the world. And in that world, the main concern is the proper administering of its rules and regulations (Gordon, 2014, p. 86).

Community rehabilitation workers (see Case Three), in some way, can play a role in disrupting this decadence because their training is, by design, interdisciplinary. While interdisciplinarity has been the response to disciplinary decadence for some time, it is not without critiques as well. For example, Gordon (2014, p. 87) problematizes it as a decadent structure too because of the presumed disciplinary completeness which allows disciplines to "simply work alongside each other like ships passing in the night." What is required then, is what Gordon calls "teleological suspension of disciplinarity" (Gordon, 2014, p. 87) which is a decolonial act that must include persons with disabilities. In IPECP that is the common approach, defined by the WHO (2010, p. 12) as "Interprofessional education occurs when two or more professions learn about, from and with each other to enable effective collaboration and improve health outcomes." The goal for collaboration must be holistic inclusion of the community. Hierarchies still exist currently where the superiority from medicine remains. Reports that look into reconceptualizing health professions education in South Africa (Volmink, 2018), show that Rehabilitation Sciences do not feature in the health professions cited. How then should Rehabilitation Sciences facilitate such a suspension of disciplinarity?

Reflective spaces for students to understand agency and structure as it relates to professional identity (Sonday et al., 2019) serve a transformative role. Hout and Rudman (2010) described this interplay further as being positioned along a continuum, affording individuals who navigate this continuum possibility of new ways of practice.

Navigating the Interplay Between Socio-Political Hegemony and Curricula

In order to counter hegemony, rehabilitation educators must resist the hegemonic pressures exerted on them as they encounter managerialism and neo-liberal cultures that constrain critical practice. Case One highlighted that being occupied by a structural system impacted on how occupational therapists chose to enact their professional agency. Sonday et al. (2019) described three mechanisms, namely, anchoring, complying and transgression whereby occupational therapists enacted their change agency in response to the varying schooling environments. Annie D struggled to transgress as she became aware of the boundaries, not only of the Western Cape Education Department, but also the imposed rules of the Occupational Therapy profession. Her attempt in resisting the dominant way of doing in that schooling environment determined how power was negotiated within a gendered hierarchical structure. The core focus of a profession like occupational therapy is to enable participation and engagement for persons with disabilities (Ramugondo, 2018). With a fundamental understanding that context plays a critical role in shaping and influencing practice and who enacts this practice, lends itself to the history of how health professionals are trained and prepared. For instance, Kinsella and

Whiteford (2009) argue that it is important to reflect on how knowledge is generated and used within occupational therapy. This reflective praxis applies to all Rehabilitation Sciences in general particularly regarding interrogating the theoretical frameworks that are used to inform curricula. Situating knowledge production at the level of the curriculum can contribute to shaping rehabilitation professionals who are socially just and competent.

The curriculum would have to pay attention to the development of competencies such as political lobbying (Kronenberg, Pollard, & Ramugondo, 2011) in order to make meaningful contributions to the disability agenda. The curriculum should address competencies such as skills to facilitate collaboration and the development of advocacy and mediation skills (AASF, 2018). In addition, it must address social policy processes in terms of interpretation, analysis, implementation and monitoring in order for graduates to acquire these skills. Likewise, students must participate in collaborative action research projects that deal with disability issues with persons with disabilities and parents of disabled children or other family members. Inviting persons with disabilities who already have these competencies, for example, writing policy briefs addressing recommendations for change (see for example Lorenzo & Janse van Rensburg, 2016), from working in NGOs or collaborative projects in the government or higher education sectors as co-educators in health sciences education is an imperative strategy towards realizing the vision of a transformed curriculum with CDS embedded in it.

In Case Three, transformational learning advocated by Mezirow (1997) has proven to be beneficial for graduates of the HCDP as they highlighted an understanding and critical appreciation of the importance and value of the inclusion of persons with disabilities in various contexts of rehabilitation. Gamiet and Rowe (2019) reflect on the perceptions of rehabilitation therapists on HCDP graduates (CRWs) from a service delivery perspective. Based on their exploration of how the role of CRWs is understood by rehabilitation professionals, their study highlighted that therapists appreciated that CRWs has a clear understanding of the context and communities that persons with disabilities come from, and are integral in facilitating active participation and reintegration of persons with disabilities.

Volmink (2018) asserts that health sciences educators need to be supported to challenge the dominant ways of training and become "agents of change" in order to dismantle dominant ways of practicing in educational spaces and the community. Duncan et al. (2006) coordinated sessions titled "conversations on practice" with educators and therapists as a change management process in order to challenge the dominant ways of practicing and to explore the implications of working with new emerging professionals in the rehabilitation domain. They reported that these conversations were not always easy; resistance and ambivalence were expressed through concerns about workload, anxieties about role boundaries and fears about the professions becoming redundant. Therapists reflected uncertainty about the level and the limits of the knowledge and skills held by these new mid-level workers and the implications of the supervisory role that therapists would have to hold when working interprofessionally with them. In addressing this issue, Ned et al. (2020), propose articulation as a strategy to decentralize training where the early years of professional training could include CRWs and be based in the community. They assert that this strategy would foster reciprocal learning and collaborative practice for all cadres of rehabilitation professionals.

Conclusion

There needs to be an intentional consideration of how transformation of rehabilitation education is facilitated at the level of higher education, policy development and implementation, as well as monitoring and evaluation of disability and rehabilitation services. This intention includes rethinking our own dominant use of theories and models of disability that do not necessarily speak to the southern realities in order to enable engagement of more nuanced understandings of disability in Rehabilitation Sciences. Given that currently the health system predominantly works within an individual, biomedical model within a largely stratified work approach with silos, rehabilitation personnel need to work more intentionally to prevent the narrow service delivery systems that undermine the potential of broader IPECP training. Graduates need to become agents of change to dismantle the current approaches to rehabilitation so that they are better equipped to work within and between CPH, CBR and CDS frameworks.

In order for Rehabilitation Sciences curricula to create the space for graduates to empower themselves to be change agents who advocate for IPECP, consciousness of power dynamics and hegemonic ways of practice that exist need to be addressed. The curriculum needs to create opportunities for them to acquire leadership competencies and advocacy skills to challenge and transform current approaches to service delivery. They need to collaborate with persons with disabilities and develop a collective voice to facilitate the paradigm shift towards inclusive and collaborative development practice. Through the cases presented in this chapter, we draw from a CDS lens a contribution towards re-imagining a critical Rehabilitation Sciences by integrating and embedding CDS that accounts for the hegemonic effects of marginalizing disability as a total social system of oppression through and beyond the body.

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Reciprocity in Knowledge Production: A Cornerstone for Disability Inclusion

22

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Abstract

The chapter is divided into three linked contributions by authors who discuss their experience of, and thinking about, reciprocity in different health care and educational settings. Christina described how the disrespectful attitude of health care staff toward her as a new mother with a disabled child led to her active engagement with community projects. Gubela has looked at a history of coloniality that dismissed the local knowledge and wisdom related to health thereby which has ruthlessly impacted on the well-being of a rural community. Lindsey and Lucia have described the process of "learning from" each other in a PhD supervision partnership.

Keywords

Reciprocity · Disability · Indigenous knowledges · Cooperative learning · Common humanity

Introduction

In Casement's introduction to his seminal book "On Learning from the Patient" (1985) he states, "*there have been some genius analysts, such as Freud and Winnicott, who learned naturally how to learn from their patients*… *Opportunities for learning from the patient are there in all caring professions*" (pg. x). This belief in the value of learning with and from the "other" is a cornerstone of reciprocity in knowledge production. It values the coming together of two or more minds to inquire, explore, and attempt to understand experiences that are essentially those of being human. With the world still reeling from the COVID-19 pandemic, this chapter seems ever more prescient as we recognize that we will not survive without knowledge exchanges across borders, community cooperation in creating safe spaces, and neighbors reaching out to those who have become isolated or unwell. Reciprocity relies on a respect for another's knowledge and experience and the recognition of a shared humanity, in other words to survive we need each other.

The following chapter in divided into three linked contributions by authors who have discussed their experience of, and thinking about, reciprocity in different health care and educational settings. Christina describes how the disrespectful attitude of health care staff towards her as a young new mother with a disabled child led to her active engagement with community projects that can assist parents and children with disabilities learn from each other and demand their rights. Gubela has looked at a history of coloniality that dismissed the local knowledge and wisdom related to health thereby creating a split system of health care, traditional knowledge, and "Western medicine" that has ruthlessly impacted on the well-being of a rural community. Lindsey and Lucia have described the process of "learning from" each other in a PhD supervision partnership.

Our hope is to add to the scholarship in critical disability studies (Vehmas & Watson, 2014) that goes beyond binary notions, of who is able and who is disabled, to considering how creating a third space of knowledge benefits all. This chapter explores how relationships built on reciprocity move beyond "doer and done to" (Benjamin, 2018) to one of shared learning and a recognition of a common humanity.

The chapter concludes with the four authors considering how reciprocity becomes more than an exchange of "goods," as it facilitates disability inclusion that is part of an overall "ethic of care" (Tronto, 1993). Some of the barriers to relationships based on mutual respect, fear of vulnerability, and an acknowledgment of the need for the other will be addressed. The authors, through the use of personal and political accounts of the barriers to, and rewards of, sharing knowledge, hope to show that moving beyond the rigid professional boundaries held by clinical staff, academic researchers and educators can provide new knowledges and nurture the emotional well-being of all.

The following section begins with Christina describing, in vivid detail, her experience of having a child with disabilities as a new young mother in a rural South Africa setting. The narrative is followed with some of Christina's theoretical reflections on the experience, with suggestions about improving the system of health care. She states there should be more joint working between parents of children with disabilities and health care staff, a form of reciprocal learning from and with each other.

The Experience of Parenting a Child with Disabilities in a Rural South African Setting

My child was born 8 months premature and was in an incubator for 1 month. When I was discharged from the hospital, I did not know that my child was disabled. I thought my child is normal like other children I did not see anything wrong to him. He has all parts of his body like other children. After some few months, I discovered that my child was not physically developing like other children of his age. He was too weak to sit upright on his own, he continued to fall occasionally, and his age group were about to crawl. I suspected that something was not right, and the health professionals would be the right people to assist. I took him to my nearest hospital and explained the situation of my child to the health professionals.

When I realized that something was not right to my child, I approached my nearest hospital, and my first point of contact was the doctor and the nurse. I presented the health condition of my child in my vernacular and the nurse translated to the doctor in English.

I was told that all he needed was to practice certain exercises and that with time he would be able to walk. I was advised to take him to physiotherapy and occupational therapy every second week of the month, but their reasons were not clear to me. I tried to ask what the cause of the disability and I was told not to worry "the child will be fine." I felt irritated because I was told the same thing over and over again, and I did not see the progress to my child.

The Emotional Impact of Parenting

I felt ashamed because I was such a young mother and I used to ask myself constantly, why I gave birth to this kind of child? What was the cause? It God's punishment? I am bewitched? These are some of the questions I cried over every day. The most painful part of all was that I could not find anyone with whom I could share my misery. I was given false hope, reassurance that his situation would get better which sounded promising. I was in and out to the hospital for therapy sessions without seeing any improvement to my child. They keep on telling me "Do not worry, he will be fine." Those words strengthened my hope because I had trust in the therapist as they know best about health issues.

The father of the child was still at school. When my mother suspected that I was pregnant she informed my aunt, and I was approached by my aunt to confirm with me if indeed I was pregnant. I confirmed with her that is true. My family took me to the boyfriend family to inform them that I am pregnant. My boyfriend refused and told his parents that he does not know anything about my pregnancy. This meeting was before the child was born.

My elder brother told me to take my child to Nthume institution for persons with disabilities because he is disabled. I felt powerless because there was no support from anyone until I was introduced to Disabled Children Action Group. There was no support from anyone, family, friends, or adequate knowledge about parenting a disabled child. It was an emotional straining to find myself being disconnected from the people I love and trusted most.

Family and Friend's Attitude

I struggled immensely at that time as I received no support from my family and friends. There was no one I could turn to for advice or even simply to talk to about the attitude from my family and friends. Inadequate emotional assistance led to an escalation of the stress I already suffered due to the circumstances. My best friends laughed at me and used to tell me that having a child is a burden, because you must carry the child wherever you go like a "handbag." At that time, the analogy seemed too moderate as my child was more than a handbag, like a big suitcase filled with stones. The burden seemed to be more I could bear. Crying was part of my daily routine as my parents were constantly angry because they expected me to go to school not to have child. Since it was my first child, I experienced stress as well as feelings of depression, anger, shock, denial, self-blame, guilt, and confusion. It was not easy at all because you have no life, no life at all. I could not go anywhere; I had not enough time to be social because I did not have anyone to help; and I was overwhelmed with stress, frustration, and fear of parenting a disabled child.

Fear of Health Professionals

I experienced a deep fear of health professionals because they were reputed to scold those who asked too many questions. The hardest thing to deal with, however, was the false promise that the child would eventually be able to walk. I really trusted health professionals and were very few in my area during that time. I thought that they knew everything, well-educated doctors who had all the answers to the problem of my child. I had expectations for my child as great as any other mother's, but as time went on, I realized that what I was told by the health professionals, mostly physiotherapists, could not come to pass.

Diagnosis Discovered Professionals Quantifying and Naming the Disability (Parents and Therapist)

I learnt the name of my child's disability was cerebral palsy (CP) when I was queuing with other parents of children with disabilities at the physiotherapy department. One of the officials came outside and said "parents of CP children should move from this queue and queue to the other side of the building." I told myself that my child's disability was CP, now I know, it was a big English word to hear it for the first time in my life, I did not realize the two letters it stood for Cerebral Palsy. When it was my turn to get in the consultation room, I explain the condition of my child and asked will he be able to walk one day? The response was "Don't worry he will be fine!!!!!".

I was told how I should stretch the hands and feet of my child when I am at home. Every time when people ask me "why you are carrying your child at your back going in and out to the hospital?", my response was my child has a "CP" problem, and that was the only answer I could give. I did not ask anything because I believed that professionals know better, well-trained medical doctors and highly qualified to do their job, and, as a result, I have to listen to and take their instruction.

Educational Assessment

When my child was 8 years old, I took him to my nearest special school for admission. The process for admission was long, because you have to take an application form to the psychology department to assess the IQ of the child. The day I visited the hospital for the psychologist to assess the child, I realized he was a white man who spoke English and I was not fluent with my English. I was stressed because there was no translator, and I could not express myself confidently in English. I put the form on his table and pointed for him to complete his part in the form. He did so without asking any questions and at the last part he wrote 48% IQ.

There was no instrument that he used to assess my child as having a 48% IQ. Because of this score, his application to the school was rejected and I was told that his IQ level was too low for admission. I went back home worried about the IQ score because the difference was 12% to make 60% for my child to get admission. I wanted my child to go to school, then I could look for a job. I went back to the psychologist after 3 months to tell him the IQ he wrote was too low for the school to accept my child. He asked me what he must write. I told him that he can write anything above 60% IQ and he then wrote 68% IQ. The head of the school then accepted the application of my child and I was just over the moon about the admission of my son. I felt helpless because at that time I could not read English or write English as a parent. I had to rely on the goodwill and actions of "expert" others.

Negative Experiences of Parenting

In writing this narrative and revisiting this painful past, there are questions I have about how health care services can meet the needs of parents who have children with disabilities. This response is particularly important when parents, as I was, do not come from privileged backgrounds of race, class, education, and socioeconomic security. Parents may not speak the English language of the medical staff, they may have little or no previous experience of disability, and they may live in rural communities that hold negative views of disability. Yes, rural areas hold negative views. My experience is more of the rural area I come from than in the urban areas.

Having no clear explanation for my child with disabilities made me vulnerable to ostracization by family members and the community. Callery (1997) claims that the integration of parental and professional knowledge has potential benefits in the management of children's health problems. It was easy to internalize the negative comments thrown at me, when there was no other plausible explanation that I could use to explain my child's disability. Studies have found that parents are also dissatisfied because they do not feel that they are respected as partners who have parental expertise and competence (Balling & McCubbin, 2001; Fisher, 2001). As a parent of a child with a disability, I was not given an opportunity to share my observations and experience of parenting my child. I was afraid to ask questions, I just have to take what I was told to do. Gona et al. (2018) assert that health professionals underestimate the emotional distress and need for information experienced by parents and carers of children with disabilities. I remember when the physiotherapy gave me pamphlets to read that were written in English with pictures of children and persons with disabilities, but I could not read the pamphlet. The information was of no use, because I could not understand the language. It was not my first language, and I could not find any help.

Fear of Societal Stigma

Having a disabled child means the destruction of parents' dreams of their ideal child (Schmitke & Schlomann, 2002). I had no social or emotional support when raising my child with a disability, and I avoided public places with him to keep him away from the community. If people saw him crawling outside, I would rush to put him on my back and hurry into the house. Dura-Vila (2010) suggested that raising a child with a disability has significant consequences for parents and family. The major problem with this system of avoidance came in the child's need to visit the clinic. On those days, I knew that the child and I would be exposed to the public, and everyone will know that I have a child with a disability. So, I devised a plan to avoid many questions.

Finding a Way Forward: The Value of Local Support Groups

The coming together of mothers of children with disabilities was a platform to share life experiences collectively to promote acceptance and equality for our children to be recognized as part of the South African future and society. The formation of Disabled Children Action Group, parents' organization, restored my dignity, gave me confidence, and reduced the stigma of the community. The organization was of vital importance because it helped to normalize my experiences of parenting by meeting together as parents of children with disabilities. Through our joint efforts as parents of children with disabilities, we share challenges, solutions, and developed strategies towards affirmation of integration and equal participation in our society.

Today, I walk tall, an active proud mother of an adult son with a disability, committed to advocate equal opportunities for and able to mentor other parents and persons with disabilities to advocate for their rights. I salute Disabled Children Action Group for having played a significant role with a wealth of information acquired from sharing knowledge through parents' empowerment workshops, trainings, seminars, and conferences. Today, I am a disability inclusion activist, and I obtained my Master's degree in Disability Studies and Doctor of philosophy.

The Future Practice for Health Professional and Parents of Children with Disabilities

Health professionals as change agents can make a difference in the lives of children with disabilities and their families in a number of ways. By using the social model of disability, health professionals in partnership with people with disabilities and parents can address sociopolitical constructs that create challenges for persons with disabilities. As can be seen in my narrative, I cannot emphasis enough the importance of the provision of early diagnosis and information to parents in the process of care and rehabilitation of their child with disability. In providing diagnoses and information related to disabilities, family members should be included wherever possible. This inclusion could limit blaming and attitudes from families and could strengthen the support base for the parents. The social model promotes opportunities for Disabled Children Action Group, parents' organization, to advocate and lobby for the rights of children with disabilities, remove societal barriers, attitude experienced, and critique the manner in which society perceive children with disabilities and their parents. The attitudes towards children with disabilities impact parents' experiences and challenges parenting children with disabilities.

The formation of local support groups at grassroots levels to provide for the sharing of challenges and information could have a positive impact on parents and the community. Continual efforts to raise awareness about the rights of children with disabilities within the society through traditional councils and community radio stations would reduce the challenges of stigma and attitudes experienced by parents within their communities. Parents of disabled children have a great role to play in the development and well-being of their children, because parents know their children better and are able to inform the health professionals about their child's development. They can help health professionals to understand their children better, they can give advice about individual behavior, and they can contribute to the design and implementation of joint learning and support strategies. It is for this reason that health professionals and parents of children with disabilities should work together to close the gap existing between parents and health professionals for the betterment of the child.

This collaboration is an appropriate responsibility for health professionals, seeing that the core values of health professionals include service delivery and the enhancement of dignity, worth of children with disabilities, parents, and society. The health professionals incorporated to local parents branches to create social networks on disability and diversity awareness programs for social cohesion. Parents share their own experiences of parenting children with disabilities to health professional forum meetings. The provision of adequate and effective information about disability management which is relevant to children with disabilities in their vernacular language through seminars. Appropriate counselling at the grassroots levels, i.e., at the local clinics. Training on food security income generating projects to unemployment parents of children with disabilities.

In this next section, Gubela Mji highlights the impact that "Western" medicine, religion, and education have had on the traditional healing practices of an indigenous African culture, the AmaBomvane, in the Eastern Cape Province of South Africa. The AmaBomvane experienced a prolonged period of symbolic violence through a process of colonization, which viewed their languages, education, health care systems, and spiritual practices as inferior to those espoused by the white Western world. The lack of respect shown by the West towards knowledge that existed over generations that are part of the healing traditions within an African context provides a powerful example of how the lack of reciprocity can lead to damaging health outcomes. Gubela ends her discussion with some considerations of future possibilities, and in this way, joins the call for decolonized learning in all health, education, and social environments. This decolonial learning is only possible if there is a genuine sharing of knowledges without privileging some as being "superior" to others, i.e., that "Western" medicine is viewed as better than traditional and/or local practices of health care. Gubela suggests that there is much to be learnt and shared with the "other," which are the elders of the AmaBomvane clan.

Hope Amid Symbolic Violence

The hegemonic knowledge of the "West," i.e., the USA, the UK, and Europe, which promotes "scientific knowledges" that are based on medical diagnosis of a single cause of a disease, which frequently is addressed by either surgical or pharmacological cures has negative impact to indigenous peoples who see health and sickness in a relational manner. This approach to patients tends to apply colonial power of imposition whereby the body of the indigenous person is something to be studied and divorced from seeing the body as belonging to a human being. This approach is described by Jansen (31 Jan 2021, cited in Mji, 2013) when describing how colonial doctors managed indigenous patients: "The crisis in western medicine is that investigations concentrated upon certain mechanisms, upon special organs, and systems to good purpose. The patient was provisionally ignored: he was merely the incidental battlefield of bacteriological conflict, or irrelevant container of a fascinating biochemical process" (Mji, 2013, pg. 46).

Unfortunately, the colonizers used this lens of imposition on all aspects of life in countries which were colonized. This colonization resulted in a tendency of choosing to be arbiters of existing indigenous knowledges systems, frequently viewing these health knowledge systems as inferior forms of health care, and describing some indigenous healers, such as amaxwele (herbalists) or amagqirha (diviners), as charlatans who use a mixture of witchcraft and trickery. It appears that Western medicine saw itself as superior, which created mistrust of the traditional practices of the village healers.

The way these new knowledges systems were introduced throughout South Africa during the period of colonization and which continued during apartheid has been seen by indigenous peoples as a form of symbolic violence. Burham (31 Jan 2021, cited in Mji (2013) shares this concern about the Xhosa people who are part of AmaBomvane:

> We are getting too one-sided in our development of the rational side of our being and getting psychologically impoverished and also severed from roots which nourish us. How can we claim to be healers when we have become technologists? Especially healers of people to whom technology has less meaning and the human being is still supreme? This difference might be partly because western technology is moving away from the essence of being human and from participating creatively with the rest of the world. The Xhosa healer is not only essential for his own people but, to some extent, for all of us (Mji, 2013, pg. 47).

The AmaBomvane People and Their Obligations

The AmaBomvane people are proud indigenous people. The highest determinant of health and well-being for the Bomvana person was to live and exist as an embodiment of the Bomvana culture, as a spiritual being who honored and practiced the beliefs of the Bomvana. The AmaBomvane believe that the highest indicator of good health is to live and exist as a Bomvana, and as such, there are certain obligations for the status of being a Bomvane. These responsibilities include ensuring that there is sufficient food to feed all families until satiety, peace, and security, looking after children from conception until maturity and giving reverence to ancestors. Since the introduction of the Western practices of education, religion, and medicine to this area, the Bomvane people now live below the poverty line with their community blighted by diseases such as malnutrition, tuberculosis (TB), and human immunodeficiency virus (HIV and AIDs).

The current Chief of AmaBomvane laments that the modern (Western) knowledge systems of delivering health, religion, and education that entered their calm existence had overlooked their daily cultural practices, which contributed to the health and well-being of AmaBomvane. The indigenous people of this area regard themselves as having been practicing education, religion, and health for the well-being of their families long before the foreign entry of Western medicine. They believe that the colonizers' introduction of Western-based knowledges undermined their civilization by introducing Western understandings and interpretations of education, religion, and health. The blatant disregard of the indigenous knowledge system of AmaBomvane by the imposition of Western knowledge can be interpreted as being a form of symbolic violence.

This Chief believes that the enforcement of these three aspects (health, education, and religion) by external agents who seemed to have assumed that the AmaBomvane communities were "blank slates" who had no knowledge and wisdom at all. This belief resulted in a fractured ill community struggling with their "beingness" and becoming, i.e., being part of an evolving community.

The Relationship Between AmaBomvane Community and Allopathic Health Care Providers

The section of this chapter will focus on the relationships between the "western" health care providers in the district hospital, their nine satellite clinics, and the AmaBomvane community.

The AmaBomvane community currently receives health services from two set of health providers, namely the allopathic health care practitioners in secondary hospital and the clinics and the indigenous health practitioners embedded in the Eastern Cape indigenous community of South Africa. These two health systems run parallel to each other, but the allopathic health care providers have assumed they are being the "better" health providers. In many respects, this high moral ground assumed by the allopathic health providers has been reinforced in the colonial education practices that are so vehemently contested in the struggle against the apartheid government.

Due to these separate and parallel health systems, there exists a subtle conflict between the indigenous health practitioners and the allopathic health practitioners that operate in the areas of Bomvaneland. Patients from this area who seek to utilize both indigenous and allopathic health strategies to manage their illness are negatively affected by the tensions with allopathic medicine and its practitioners belittling the indigenous health practitioners. The AmaBomvane view health as dependent on the status of relationships between the individual, the family unit, the community, the ancestors, and the environment. Illness is seen as result of these broken relationships (Mji, 2013). For the AmaBomvana, it is more important to prevent illness rather than to cure it, so their indigenous health system is focused on strengthening these relationships rather than curing physical disease (Mji, 2013).

Due to the general level of mistrust between the allopathic health professionals and the indigenous healers, many patients and their relatives try to contain the health situation "on the quiet" by using indigenous health advice before visiting the hospital or the clinic. This practice frequently results in them being chastised by health professionals for attempting to use what is seen as an "inferior" medication when their relatives are sick. What is misunderstood is that many households are located quite far from the hospital and the indigenous healer is the only resource available to them, especially at night. The condescending attitude and critical approach by health professionals creates a deep mistrust, with health professionals perceiving the patient as having used some form of "voodoo muthi" prior to coming to the health center. Because of this situation, people using these services opt for a veil of secrecy as they feel stigmatized, chastised, and ashamed of the indigenous health knowledge (IHK) they have sought and used prior to coming to the allopathic health center. In many ways, they feel silenced by the allopathic health providers who appear to be the knowledge holders on the issues of allopathic medicine and the power it exudes in the area on matters related to health. This conflict makes it appear that there is no will to accommodate other approaches to health care, including IHK, which is still widely practiced by this community. As the battle to take control of health matters by the allopathic health providers and to silence the people of this area of the IHK continues, within the Bomvane culture, there is a group of older women who see themselves as practicing healing from a standpoint of humility and without duress. They are the valued and valuable IHK practitioners. They have carried the traditions and knowledge from generations of their forefathers, and they practice a deep wisdom of knowledge that connects the environment with the health and well-being of its inhabitants.

Elite Older Women as Agents of Health and Care

I draw this proposition from an ethnographic study that explored the IHK carried out by the Bomvane older women in their home (Mji, 2013). This study revealed a wealth of health-related knowledge carried by the Bomvane older women in supporting their relatives when they are sick. It was further ascertained that these Bomvane older women, when their IHK strategies were not helpful in improving the health status of their relatives, went out of the home to consult other older women who are known in their villages for dealing with the type of illness that had afflicted their relatives. Mji (2013) classified these women as the elite older women. Elite groups comprise influential, prominent, and well-informed people who occupy important positions and whose behavior is associated with those positions. They are expected to hold the basis of expertise, valuable information, and an overall view of the social organization in their villages. I argue that the older people in indigenous communities such as KwaBomvana can become more powerful and autonomous in old age, taking on new roles and duties.

The elite older Xhosa women of KwaBomvana have shown excellence in the management of the health of the home by developing a bridge between natural indigenous herbs of their area and the home. They have strengthened the concept of "humility," health, and survival as a collective by sharing their knowledge of healing practices within their community. However, with the imposition of Western health knowledges, the voices of these older people, especially women, are rarely heard now in debates about health. Consequently, there has been little research that explores the ways in which the older women contribute to the health economy and social capital of their communities. In Bomvanaland, the "new knowledge" holders that have entered carrying their perception of a superior way of dealing with knowledge related to health, education, and religion have disrupted the quiet existence of the AmaBomvane people.

As a result, the education on matters of health and spirituality that has been delivered to the young by the Bomvane older women has been ignored and frequently criticized by the allopathic health care professionals in the area. Alongside this dismissal of the wisdom of these women, South Africa has a high prevalence of HIV and AIDS frequently related to the economic migration patterns of young adults living in rural communities. The high prevalence of HIV/AIDS and migration patterns has meant that many older people, specifically women, have become the pillars of their communities and carers for orphans whose parents were lost to AIDS.

Clough (1998) suggests that the talents of women have been carefully integrated into their day-to-day activities, so much so that these talents have been classified and simplified as part and parcel of "the role" woman are seen to fulfill in society, for example, terms such as "labour of love" are commonly and loosely used. Boneham and Sixsmith (2005) suggest that women's dual roles as caregivers, especially those caring for persons with disabilities, have been underestimated. They claim that a gendered evaluation of health and health care is more likely to position the older women in a more positive light and construct the older women as active agents in health matters, especially concerning their family. The role that the older women take on in fostering a spirit of belonging, participation, and identification of local assets, such as IHK, in their local community needs to be recognized by allopathic health providers and claimed by the community as a legitimate health resource. The women's contribution to the young in facilitating the unlocking of internal power and resilience through storytelling, which further builds character, deserves recognition by all.

According to the Bomvane older women, there is a strong relationship between relationships and sickness. They see nurturing relationships through respect, with older people respecting young people and vice-versa, as the cornerstone to good health with healthy homes making healthy villages. They see part of their contribution to healthy villages is to assist in nurturing the youth to be respectful individuals who understand the culture of AmaBomvane and participate respectfully in the activities of their villages. Like the Maori (Durie, 2004), by whom health was measured according to their participation in tribal activities, being included in family celebrations and the ability to make Bomvane beer for ancestral reverence served as a yardstick for wellness. Being healthy entailed being fully engaged in the functions of AmaBomvane people in a respectful culturally acceptable manner (Jansen, 1973; Bùhrmann & Gqomfa, 1981, 1982); Bùhrmann (1983, 1984, 1987). This participation in village activities was and is the yardstick that is used for measuring the health status of an individual in their villages.

Lately, the healing vocation and knowledges of the Bomvane older women are at risk of being lost because of the changing mores within their community. The migration of the middle generation of AmaBomvane families to the cities for economic security, with some dying of HIV and AIDs, has left the Bomvane older women having to change their roles. Previously, they were the educators of the young, and now they must undertake the heavy duty of caring for the home and their young grandchildren.

In view of the challenges that the Bomvane older women are currently facing, I have considered if the current (and Western) education systems in the area could assist with supporting the older people in these rural communities in managing the pressures, risks, and anxieties of this modern living? In other words, can there be a reciprocal sharing of resources and knowledge that can allow for a mutual exchange of wisdom. For example, can the social media resources of Snapchat, WhatsApp, and Facebook as mobile technologies that can deliver information and offer support networks, be of assistance for the older people in indigenous communities such as KwaBomvana? Can the existing allopathic health care systems and educational institutions in this area respectfully join hands with the older people of this community through a mutual enhancing of the health of the home? While there is also a possibility of doctors and health professionals trained in Western medicine working collaboratively with the elite older Xhosa women and indigenous healers. As part of decolonizing the curriculum, elite women could be integrated within the school system, teaching the youth of their culture and health remedies. One of the biggest challenge is that the carriers of indigenous health knowledge are dying with this knowledge system. Could the new technologies capture and transform the important role that is played by the older people as knowledge holders and reservoirs of experiential knowledge for future generations? These technologies could be used to capture oral history and stories as knowledge and evidence of health practices which could be used as reservoirs of indigenous health knowledges and used to decolonize the health science curriculum.

In the final section of this chapter, Lucia (a PhD student) and Lindsey (one of her two supervisors) discuss how they have worked together and learnt from each other. This journey of mutual learning was in many ways unexpected and has brought many rich rewards for both. Lucia has more confidence in her self-knowledge and thinking, and Lindsey is now less fearful of serious long-term mental illnesses, her own and those of the students and clients that she meets.

Learning from and with the Other

The supervision of a PhD project brings many rewards and challenges. As the journey begins, it is never clear how it will develop, and so many different factors can come into play in a process that can take between 4 and 8 years. To our knowledge, there has been a PhD thesis written about the experiences of students in a supervisory relationship (Kirkland, 2018), and a psychosocial understanding of the parallel dynamics that can occur in supervision alongside the topic (Jervis, 2012). In many ways, what Lucia and Lindsey are writing about is echoed in the seminal work of Casement, published in 1985, “On Learning from the Patient.”

In this section, Lucia and Lindsey look at what reciprocity means in their work together as supervisor (Lindsey) and PhD student (Lucia). The study is on trauma and psychosis, and Lucia has chosen an autoethnographic methodology that uses a psychoanalytic analysis of her lived experience of psychosis and recovery. Lindsey begins with her reflections on being a PhD supervisor, and Lucia continues the story with her experience of being supervised. The reason for Lindsey to “go first” in this section is to contextualize a pivotal moment in their relationship, which, before writing this chapter, neither Lucia nor Lindsey had fully recognized or discussed with each other!

Lindsey Writing About Her Relationship with Lucia

What has been essential, in my experience of postgraduate supervision, is a need for an authentic relationship between the student and the team of supervisors, and a genuine interest in the topic. To date, I have been very fortunate with regards to these “essential” elements. Each student and each topic have illuminated my knowledge and understanding of the subject, and all the research projects have endeavored to understanding human beings and their relationships with the world.

In a recent Times Higher Education (THE) article, Buitendijk (2021:2) suggested that “universities should partner with students instead of treating them like passive recipients of our supervisor knowledge.” These seemingly glib words, which echo much of the popular call for “student led” education, do not convey the wonder and delight that I can have experienced in learning with and from Lucia. It also does not express the deep fears I had as the PhD began about Lucia's well-being and the times when I have taken comfort from her discussions on the lived experience of her psychosis.

Meeting Lucia

In 2012, a university colleague, Professor Wendy Bryant, asked me if I could meet with one of her research assistants, Lucia Franco, who had written an account of her psychosis. In her essay Wendy had told me, she had mentioned Freud. "You know about that Lindsey," she said, and left Lucia and I to make contact. I read Lucia's account of her psychotic illness and her exploration of its origins. It was remarkable, Freud was indeed mentioned in it, and Lucia had written a description of a traumatic event that occurred when she was a young woman and followed on with an in-depth analysis of its long-term consequences. Lucia and I had many conversations over her writing style, not the content, and the following year Lucia had it published in a journal (Franco, 2013). Lucia asked me one day, "do you think I could do a PhD on the topic of how the unconscious layering of trauma could lead to psychosis (her hypothesis)?". "Absolutely," I answered. What I had not anticipated was the hurdles created to her registration by health science research committees that were afraid she would cause harm to others by exploring their experience of psychosis and that her methodology would not lead to empirical evidence. She was finally accepted by the social science faculty, whose senior researcher, Professor Dany Nobus, said he had seldom read such an eloquent and well-reasoned PhD proposal.

Lucia is in the final part of writing her thesis. We meet regularly and I enjoy our conversations. She never takes knowledge at face value and has read the original work of key psychoanalytic authors to make sense of their theories. She has seen links between Bion's work on thinking with Winnicott's formation of the "false self." She has read the work of Ferenczi (recently "back in fashion" in psychoanalytic thinking) and she has summarized and interrogated their work. She has explored the work of Searles and recently she and I read Bollas's description of his analytic work with people in the acute stage of their psychosis: "Catch them before they fall" (Bollas, 2012).

Lucia, having experienced many psychotic episodes, has recovered and returned to explore their meanings. She is a person whose experience is applied to theory, and not the other way round. She will argue that in her experience it is important to know the cause of a breakdown, not simply say "it cannot be known." She does not accept that all emotional vulnerabilities develop in childhood and her long-term goal is that health professionals should listen out for the experience of trauma which may be hidden within psychotic symptoms. Without this knowledge about the meanings of the symptoms, the illness may persist. All these things I have learnt from Lucia. I did not know them before. She has used theory to test it against her lived experience. At times, it seems to have given her validation and words to express her understanding; at times, it frustrates her because she knows something different.

There is a term used in the UK for people who offer educational programs insights based on their experience; they were previously called “service users” and now the term is “expert through experience.” I think that this too can be a glib term, unless like Lucia, they have used their experience in the service of further knowledge. Her methodology is autoethnographic and so she tests her experience against the published knowledge of others. She has said that doing much of this work has allowed her to recover.

Breaking Down and Breaking Through My Fear

There was a moment last year, when I had met Lucia to discuss her work, when I felt a wave of deep sadness pass over me. She had told me that with the work she was doing, many of her symptoms were receding and, with it, she was able to feel connected to others and could enjoy things again. I began to think this was more than surviving her illness but moving beyond it into a world of color and appreciation. I asked her “Do you feel joy now?”, “Oh yes” she said, “I have the full range of feelings now.” I began to cry, I could not stop it; Lucia smiled at me. I was pleased that she was well and remaining well, and at the same time, I was filled with a sadness that for many years she had suffered from an absence of recognition of her illness and, at times, outright discrimination because of her “diagnosis.” This discrimination was time lost, never to be recovered. Perhaps it was also my sadness that I could have done more, done better, if only I had known what I had come to learn from her about people who had psychosis. I had been afraid of psychosis because of the way the symptoms had been explained (taught) to me with an emphasis on medical language, e.g., “delusions of grandeur,” “paranoid features.” This medical model language does not describe or seek to understand the experience of that person, or their attempt to communicate with others. Now I see psychosis as a symbolic language, and an attempt by the person to communicate their distress and confusion, in other words, an attempt to connect with another mind that is willing to listen.

Lucia Writing About Working with Dany Nobus and Lindsey

One of the consequences of being diagnosed with paranoid schizophrenia is that suddenly you are not considered a valid and responsible human being. “What I say may not be real, I do not know what I am talking about.” Things are changing compared to 40 years ago when I was first diagnosed with paranoid schizophrenia; at the time, an old-fashioned psychiatrist said to me “You are abnormal now and you have to accept you will be abnormal for the rest of your life.” While I do not think anyone would say that to me now, I find that a little of this attitude is still in many.

Confidence and Self-Belief Building

When I started working with Lindsey, I did not believe it entirely when she complimented me on my work or my understanding. I had lost belief in myself, and it was hard for me to accept her words as real. However, Lindsey's initial work with me on an article I had written gave me the courage to try and publish it. I trusted that if she thought that my work was good enough to publish, then I had to try. I was also feeling more confident about her having helped me with the writing. Gradually, over the years, I was doing my PhD research, under Lindsey and Prof. Dany Nobus's supervision; I have become more confident, more able to believe in myself, in my abilities, and in my work. This confidence is something that I understand to be normal when doing PhD studies with regular supervision. In my case, however, my being taken seriously, my gradually realizing that I was indeed understood and valued by Lindsey, contributed greatly to my improving my mental health and, in turn, I believe, my academic work abilities.

That day, when I could see the tears in Lindsey's eyes, at my expressing my newfound ability to experience joy and other feelings, was perhaps the most crucial moment that told me that she had understood how my condition affected me and how much I was improving. My feeling understood by Lindsey has played an important part in my being able to feel connected to others. My alienation from people, which was a consequence of prejudice (mine and others) and my condition, started to diminish considerably after that event. That meant that my research felt more real and meaningful, but also my life with others became more meaningful. This shift happened gradually, but it came from feeling really understood.

I never felt a psychiatrist to be understanding when I spoke of my improvement, nor did I normally feel them believing in the self-analytical work I had been doing. I think that believing what people with psychosis say, and believing in their capacity to understand themselves, can contribute both to their mental health and increase other people's understanding, while reducing prejudice. It can also improve sufferers' abilities to achieve better work and status in society.

One aspect of my research focuses on how a false self becomes central in psychosis and how the true self remains hidden and unable to find expression. Researching other theorists has given me more insight into my psychosis that has allowed me to progress further in my recovery. The entire process of doing the research has helped in recentralizing my true self.

Continuing Prejudice and Discrimination

I once tried to publish in a journal that focuses on psychosis; one reason why I was rejected was that as an autobiographical article, it had to be shorter and only academic articles could be that long. I am still puzzled, as I thought that doing PhD research studies qualified me as an academic. Other journals give the reason for rejecting my papers, as they are not publishing auto-ethnographical works but focus on professional writings. I am still puzzled. I have accepted that this battle will continue. It has been the focus of my life to go against discrimination and prejudice. In my research, I try to make psychosis intelligible and not a crazy, meaningless phenomena.

Where the Difficulty Can Lie

When the university initially had difficulties accepting my research, I was not particularly affected by their attitude. This was not because the matter was not upsetting, but rather because, since my diagnosis, I have repeatedly encountered resistances from the whole of society from recognizing and accepting my skills and abilities. I have learned to live with it.

Society said, and largely still says, I am potentially dangerous, I cannot be relied on, and I cannot be trusted. The university was only following what the medical model has repeatedly said about schizophrenia. Society fears schizophrenia and often fails to see the human being behind the diagnosis. Who I am and what I am capable of was not in focus.

I am not advocating a total disregard of the knowledge provided by medical science concerning schizophrenia or psychosis, but I am advocating a more holistic approach where the individual is considered from its entire humanity, not only from the partial, incomplete view of one model of understanding. We still do not fully understand psychosis, and many of society's fears are fears of the unknown. An open attitude of wanting to learn from the other is necessary, rather than the defensive approach of a medical diagnosis, predetermined treatment solutions, and prognosis predictions that can prevent knowledge and understanding emerging from the coproduction of knowledge between patient and therapist.

Some Further Reflections

The PhD research has been a source of difficulties; I had a psychotic episode at one point and some of the writing on the topic I found contrary to my understanding in general. It is hard work to study and research, especially in the recent COVID-19 situation, where being isolated and not seeing my supervisors in person often felt discouraging and reduced my motivation to persevere in my research studies. It has also been a source of joys and rewards. I have overcome the difficulties with the help of my supervisors, and the joys and rewards have been made more possible by the relationship of mutual respect and understanding provided by the supervision relationships I have had.

Concluding Comments

In Saban's (2019) book "Two Souls Alas," a critical reflection on the work of Carl Jung, he quotes:

> For two personalities to meet is like mixing two different chemical substances: if there is any combination at all, both are transformed. In any effective psychological treatment, the doctor is bound to influence the patient; but this influence can only take place if the patient has a reciprocal influence on the doctor. You can exert no influence if you are not susceptible to influence. (Jung, 1929, para.163)' pg. 182.

This quote supports the emphasis in this chapter that to learn with and from the "other," there has to be an acknowledgment of vulnerability on the part of the "doctor," i.e., therapist, health professional, academic researcher, etc. In the field of disability studies, this reciprocity of vulnerability has been an ongoing concern since the "nothing about us without us" political slogan became an embedded philosophy in academic institutions and an ethic of care in all health care organizations. But here is the rub: many people in positions of power and privilege find it hard to forgo their sense of importance, even a belief in their omnipotence. What may lie behind this sense of ultimate authority is a projection of frailty, neediness, and vulnerability onto those who are seen as "other." Hoggett (2000) has described the "hatred of dependence" that is embedded in neoliberal cultures of individualism and competition with others. Vulnerability is seen as existing in others, not ourselves, and this view perpetuates the notion of "survival of the fittest," as Benjamin in her later work describes, only one can survive. What this way of thinking and being in the world does not recognize is how we are irreconcilably interdependent on each other, a world view encoded in the African term "Ubuntu," encompassing a value of our humanity being bound up in each other "I am because you are" (Archbishop Desmond Tutu). How then can we move beyond the binary positions of able and disabled, or as Benjamin (2018) puts it, of "doer and done to"?

We have proposed that by establishing authentic and reciprocal relationships, we can learn from and with the "other," which potentially creates new knowledges, and perhaps more pertinent offers health care providers and academic institutions with the emotional support to continue their work. This notion of establishing reciprocal relationships moves beyond the idea of work having an emotional cost or being an "emotional labour" (Smith, 1992). We have described the emotional gains and intellectual benefits of such partnerships; it is what we have termed "love's labour found."

To return to the work of Benjamin (1990), she has said that when the dynamics of opposition, oppression, and hatred can be survived, there can be an emergence of love and an appreciation of what the "other" can bring.

> Winnicott's thesis suggests a basic tension between denial and affirmation of the other (between omnipotence and recognition of reality) . . . The wish to absolutely assert the self and deny everything outside one's own mental omnipotence must sometimes crash against

> the implacable reality of the other. . . .When the destructiveness damages neither the parent nor the self, external reality comes into view as a sharp, distinct contrast to the inner fantasy world. The outcome of this process is not simply reparation or restoration of the good object, but love, the sense of discovering the other. (Benjamin, 1990, p.192)

The last 2 years of COVID-19 has shown us how much we need to rely on each other, from neighborhood schemes and support networks to check on vulnerable or shielding persons through to sharing worldwide research evidence and hopefully, very soon, the distribution of resources from countries who have an excess of vaccines to those who do not have enough. We, the authors, sincerely hope that by sharing our experiences and knowledges within this chapter, we will encourage all therapists, researchers, and persons with disabilities and their family members to form active and critical partnerships that extend what is known, understood, and communicated about (in essence) being human.

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Leadership and Disability Studies: Inclusive Development

23

Colin Barnes and Simon Prideaux

Contents

Abstract

There can be little doubt that sociology has played a key role in our understanding of the process of disablement. Yet most sociologists have ignored the onset of disability as defined by activists and organizations controlled and run by disabled people. As a response, the latter half of the last century saw the rise of a radical critique of conventional thinking and research on disability in universities and colleges. All of which ultimately led to the creation of a new interdisciplinary area of critical enquiry: that of disability studies. Consequently, this chapter traces the origins and subsequent activism of these developments with reference to world-leading protagonists in the United States of America (USA) and the United Kingdom (UK).

Starting with the onset of capitalism and its detrimental effects on disabled people, this chapter demonstrates how the re-interpretation of disability by disabled activists during the 1970s has had an important impact on the perceptions and analysis of disability within and beyond universities and colleges in the UK and the USA. Although these developments were to be welcomed – as it signified a growing recognition of the importance of the issues raised – it also, as

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the chapter illustrates, needs to be treated with some caution. In particular, the recent and growing individualization of disability studies within the academy by some disability scholars signifies nothing less than a reaffirmation of traditional academic values and the effective de-politicization of the discipline with little relevance beyond the sterile confines of the university seminar room. Accordingly, the chapter argues it is a prerequisite that this stance is overcome and subordinated to the social model of disability in order to fully instigate a tangible sense of social justice/inclusion. Only then can the difficulties and obstacles facing disabled people be effectively opposed and overcome.

Introduction

There can be little doubt that sociology has played a key role in our understanding of the process of disablement. Yet most sociologists have ignored the onset of disability as defined by activists and organizations controlled and run by disabled people. In the latter half of the last century, for instance, this phenomenon generated a radical critique of conventional thinking and research on disability in universities and colleges. All of which ultimately led to the creation of a new interdisciplinary area of critical enquiry: disability studies. Initially, however, disability activists and writers working in disability studies played a crucial role in reshaping our knowledge of disablement. Nevertheless, such a state of affairs often resulted in an uneasy relationship between organizations controlled and run by disabled people and social scientists. By contrast, recent years have witnessed a significant deterioration of this antagonistic relationship and, as a consequence, raised serious questions about the future of disability studies and the struggle for a fairer and more just society (Barnes & Mercer, 2010; Oliver & Barnes, 2012).

Consequently, this chapter traces the origins of these developments with reference to the United States of America (USA) and the United Kingdom (UK). Most definitely, disability activism in these two countries has had the greatest influence on the development of disability legislation and services both nationally and internationally. That said, special emphasis is given to the UK as it is there “where both the social model of disability and the academic discipline of Disability Studies first developed” (Slorach, 2016:14). To begin with, though, this article looks at the challenge – dating back to the turn of the twentieth century – to orthodox thinking on the processes of disablement and the politicization of disability by disabled people and their organizations. In turn, the writings of disabled activists and their organizations, the emergence of disability studies, and its subsequent influence beyond academia will be examined.

The Politicization of Disablement

In the broadest sense, the politicization of disability can be linked to the rise of capitalism in the middle of the nineteenth century, working class activism, and the rise of the labor movement. Certainly, the accompanying “charity ethic” led to a growth of charitable organizations concerned with the welfare of the “handicapped”: notably the “blind,” “deaf,” and “crippled” (Topliss, 1979). Indeed, these groups were relatively successful in raising public awareness and encouraging the state to take some responsibilities for their welfare. However, these organizations were controlled by non-disabled people and so perpetuated the notion that disabled people were objects of charity and unable to take control of their own lives. In turn, this resulted in a growth of sheltered workshops for specific groups of disabled people and eventually the politicization of disability by disabled activists themselves.

A notable example of which is the *National League of the Blind and Disabled* (NLBD) which was an organization run exclusively by disabled people. Emerging out of sheltered workshops “for the blind” in 1893, the NLBD was affiliated to the Trades Union Congress (TUC) in 1902 and the Labour Party in 1909. By employing what today would be termed direct action, the NLBD went on to fight for employment rights and benefits. Under the banner “Justice Not Charity,” they organized a march of blind people from the north and south west to Trafalgar Square, London, in 1920. This action was the push that led to the introduction of the “Blind Persons’ Act” (1920). In many respects, this Act was the forerunner to legislation “making money available to assist disabled people.” Yet despite this apparent gain, they had to organize another march in 1933 against low wages and poor working conditions (Barrett, 1996:40).

These trends continued well into the twentieth century, and it was not until the arrival of Britain’s welfare state – with its principle of “cradle-to-grave security” (Beveridge, 1942) – that further changes occurred. This meant that the then labor government took complete control over state welfare provision for disabled people and their families. Although the government was theoretically responsible for all disability services, representatives of established charitable agencies were concerned that this undermined their role as service providers. In turn, this resulted in a complex mixture of provision by state-run local authorities and an expanding voluntary sector often subsidized and supported by the state. Prominent examples of which included *The Spastics Society*, started in 1952 (and re-named *SCOPE* in 1994), and *The Leonard Cheshire Foundation* founded in 1948 (Oliver & Barnes, 1998).

Despite the affluence of the post-war years, and the increase in public services, it quickly became apparent that disabled people and their families’ needs were not being met. And even where their needs were acknowledged, provision was often inappropriate and oppressive. Notable examples included the segregation of disabled people into long-stay hospitals for the “chronically sick and disabled” or residential institutions for “severely” disabled adults (Oliver, 1983) and the segregation of disabled children into “special schools” (Barton, 1986). There was also a growing awareness of the poverty and deprivation among disabled people and their families due to the escalating costs of living with impairment in a disabling society (DA, 1975). By contrast, growing disillusionment among service users generated a realization that if they wanted better services and benefits, they had to get involved in alternative provision and protest. This disillusionment prompted the rise of self-help and user-led organizations (Oliver & Barnes, 1998).

Conflicts between inmates and staff in long-stay hospitals and residential homes generated calls for community-based support (or “independent living” as it came to be known) alongside appeals from the “National Campaign for the Young Chronic Sick

(NCYC)" as many young disabled people were having to live in "geriatric hospitals" (Davis & Davis, 2019). To make matters worse for disabled people, the turn of the 1950s witnessed Britain recovering from the austerity and poverty of the war years, and the economy was beginning to boom. But for most disabled people and their families, it was "just as bad as it had always been" (Campbell & Oliver, 1996:52).

The campaign for a national disability income then emerged as a way of helping disabled people receive a share of the affluence emerging at that time. A major player in this campaign was the *Disablement Incomes Group* (DIG). Formed in 1965, DIG was important because – despite not being an organization strictly controlled and run by disabled people – it was led by disabled activists Megan du Boisson, Mary Greaves, and Peter Large. It also brought together other advocates with variety of differing impairments. Later, however, Peter Large and colleagues formed the *Association of Disabled Professionals* (ADP) in 1971. DIG, on the other hand, started in 1974 the *Disability Alliance* (DA) which was a broad-based coalition of organizations of and for disabled people in pursuit of a "comprehensive disability income" (DA, 1975).

Significantly, the formation of DIG brought together several disabled activists who would later become key figures in the formation of Britain's disabled people's movement. These key figures included Paul Hunt, Vic Finkelstein, Ken and Maggie Davis, and Rosalie Wilkins who quickly became disillusioned with the single-issue approach of DIG and the DA (Campbell & Oliver, 1996). Paul Hunt, a disabled resident in "Le Court" (the first "Cheshire") home, is widely regarded as the driving force in the development and politicization of disability in Britain during the 1960s and 1970s. As well as producing the first important book of essays by disabled people about living with disability (Hunt, 1966), discussed below, he inspired others by writing about disability in the popular press, disability journals, and newsletters. He also wrote numerous letters of encouragement to disabled people seeking advice and was pivotal in residents' struggle for control of their situation in the "Le Court" institution by organizing strikes and a management takeover (Hunt, 1966). In collaboration with others, he founded the *Union of Physically Impaired Against Segregation* (UPIAS) which provided the infrastructure and fundamental principles for future political representation for disabled people (Campbell & Oliver, 1996).

At the turn of the 1960s, the tension between those favoring the single-issue incomes approach of DIG and DA, and those inclined toward the more radical oppression approaches, had intensified. In response, Paul Hunt placed a letter in the *Guardian* newspaper which was instrumental in the formation of UPIAS:

> Severely physically handicapped people find themselves in isolated unsuitable institutions where their views are ignored, and they are subject to authoritarian and often cruel regimes . . .I am proposing the formation of a consumer group to put forward nationally the views of actual and potential residents of these successors to the workhouse. We hope to formulate and publish plans for alternative kinds of care . . .[we] would be glad to hear from anyone who is interested to join or support this project. (*Guardian*, 20th September 1972:no page)

Although Hunt received responses from a few disabled individuals, notable examples included Vic Finkelstein, Ken and Maggie Davies, Dick Leeman, and Rosalie

Wilkins, most responses came from charities and non-disabled people asking for more information. Consequently, he circulated the same letter to journals and newsletters of other disability organizations including the "Magic Carpet" newsletter of the apolitical *Disabled Drivers Association* formed in 1948.

Over its lifetime, UPIAS had around 141 members including 40% women and 60% men. Membership is probably being at its highest in the mid-1970s with around 50 members. Annual membership was £I or less for applicants who could not afford it and was only open to disabled people. Associate members could attend meetings, but not take part in policy discussions, nor vote or hold office. At the outset it was agreed that UPIAS was not a charity or a limited company. The group operated through a series of circulars in which all decisions regarding the election of officers, policy, and practice were open to discussion. Eighty circulars were produced between 1973 and 1990. And, in many ways, the content of these documents was like the conversation threads in the social media platforms of today (Baldwinson, 2019).

In response to criticisms that UPIAS was only concerned with issues relevant to people with physical impairments, Hunt sent a proforma to enquirers in 1975 which stated:

> We want to stress that the Union does not claim to represent or speak for other disabled people. On the contrary, we recognise that conflicting views exist amongst disabled people, and we wish to make clear what these differences are. (Baldwinson, 2019:9)

Widely regarded as a "think tank," UPIAS was the political vanguard that worked alongside non-members in various forums. Its involvement was considered important for adding clarity of thought to others' policies and campaigns: hence contributing to a further growth of user-led disability organizations in the 1970s. Important examples include the *Spinal Injuries Association*, 1974; *National Union of the Deaf*, 1976; and the *Liberation Network of Disabled People* (LNDP) in 1979. In 1975, core members Vic Finkelstein and Rosalie Wilkins were involved in the development of Britain's first television program, *Link*, which dealt purely with disability issues (Barnes, 1992).

Moreover, UPIAS members also became more aware of disability activism in other countries. Their records showed that Paul Hunt had been in ongoing correspondence with the *Anti-Handicap* project in Sweden and activists in Germany, New Zealand, and the USA (Baldwinson, 2019; 12). Of particular interest were alternative solutions to residential care. Examples included the *Fokus* project which started in Sweden in the early 1960s and subsequently spread to Denmark, Holland, and West Germany. The Fokus project involved the construction of wheelchair access to housing with 24-hour support staff for disabled residents (Ratska, 1996), and, when following its lead, this led to the development of Britain's first-ever user-led "care" attendant scheme by the Spina Injuries Association (SIA), a founding member of UPIAS, and the *Grove Road Integrated Housing Schem*e which opened in 1976 (Davis, 1981). Two years later, the *Disability Information and Advice Line* (DIAL UK) followed (Davis & Woodward, 1981). Both of the latter involved Ken and Maggie Davis.

By the late 1970s, UPIAS membership was in decline. Some members had become inactive; others felt that UPIAS thinking had become muddled and too theoretical and should pay more attention to policy instead. Non-members viewed UPIAS as elitist and male dominated. Further, UPIAS morale was dealt a bitter blow by the death of its founder, Paul Hunt, on the 12th of July 1979. He was only 42 years old. By 1981, however, United Nations (UN) held its first *International Year of Disabled People* (IYODP) which acknowledged the UPIAS idea that society needed to change in order to eliminate the exclusion of disabled people. When UPIAS proposed that the growing number of organizations controlled and run by disabled people should come together to form a national umbrella organization or council, it received widespread approval and support. On the 13th of June, UPIAS chaired a meeting of eight organizations controlled by disabled people to discuss this idea with five other organizations keen to be involved. It was agreed that this new umbrella organization should be called the *British Council of Organisation of Disabled People* (BCODP).

A steering committee was put together, and its first meeting was held 3 weeks later which produced a draft constitution. The establishment of BCODP triggered a further growth of user-led disability organizations. Although it was initially criticized for its failure to address questions of impairment, gender, racism, learning difficulties, and mental health, by 1995, it had 106 member organizations representing over 400,000 disabled people (Campbell & Oliver, 1996:182).

In 1981 the increasing politicization of disablement globally prompted the formation of *Disabled Peoples International* (DPI), an international umbrella for organizations run and controlled by disabled people. It emerged out of the anger of 200 disabled delegates at a two and a half thousand strong *Rehabilitation International* (RI) conference held in Winnipeg in 1978, Canada. They left because they were refused representation on the organizing committee for the forthcoming 1981 IYODP. Three BCODP delegates – Vic Finkelstein, Stephen Bradshaw, and Francine White – attended the DPI's first world congress (Driedger, 1989). Indeed, the relationship between BCODP and DPI lasted well into the new millennium (Oliver & Barnes, 2012).

Besides having a major impact on policy and practice across the world, disabled activists and their organizations generated a wealth of data with their books, policy statements, articles, and research reports. Even though much of this work had little impact on the social sciences generally, it did, nonetheless, form the bedrock of what would later become disability studies. Unlike developments in Britain, however, disability activism in the USA began in American universities. Consequently, we begin our discussion of the road to disability studies with events in America.

The Arrival of Disability Studies

Although there was an upsurge of disability activism during the "Great Depression" of the 1930s by the *League of the Physically Handicapped* in New York, its impact was limited by the onset of World War II. The post-war disability rights movement began with the admission of a polio survivor with quadriplegia, Ed Roberts, to a new residence program at Berkeley's University of California in 1962 (Slorach, 2016; 129). Inspired by the American civil rights movements, Roberts became a role model for other disabled people who joined him on campus. Together, they campaigned for self-advocacy and services with which to live independently. And on receipt of a grant from the US Office of Education, they formed the *Physically Disabled Students Program*. It was the first of its kind on a college campus and the beginning of the *American independent living movement* (ILM). By challenging the core American values of self-reliance and consumer rights, they demanded an end to medical professionals' control of disability policy and the incarceration of disabled people into institutions. The first center for independent living (CIL) opened in Berkeley California in 1971, providing peer support, referral services, general information, and advocacy training (Shapiro, 1994).

The rhetoric of independent living and the idea of CILs quickly spread across the USA. A major catalyst for the further development of these ideas was the 1977 White House Conference on Handicapped Individuals which attracted over 3000 delegates. This conference triggered the production of a host of books and articles on disability by academics and activists in the USA and Canada. Much of this work is linked in one way or another to structural functionalism (Parsons, 1951), role theory (Kasserbaum & Bauman, 1965; Gordon, 1966; Saffillios-Rothschild, 1970), symbolic-interactionism (Bowe, 1979; Davis, 1961; Goffman, 1961, 1963; Scott, 1969), and health.

Erving Kenneth Zola, also a polio survivor, made a substantial contribution to the development of disability studies in America. He was a trained medical sociologist at Harvard University, and his dissertation explored the different perceptions of pain and behavior when accessing medical help in three cultural communities: Irish Americans, Italians, and Jews in Boston (Zola, 1996). He was also chair of the medical sociology section of the American Sociology Association, the founder of *Disability Studies Quarterly*, and a founding member of America's *Society for Disability Studies*. As a scholar in the symbolic interactionist and pragmatist traditions, his later work focused on the experience of impairment and disability and "the universalising of disability policy" (Zola, 1989).

Nonetheless, the emphasis on rugged individualism, free market capitalism, and the American brand of democracy, which has remained remarkably consistent over centuries, continues to effect how disability is defined and responded to in the USA. Hence, disability is typically perceived as an individual medical problem "with which the disabled person must deal." Consequently, and with a few notable exceptions such as Davis (1995), Charlton (1998), and Russell (1998), American disability studies was "characterized by a general lack of historical sensibility and disconcerting insularity" throughout the 1990s (Albrecht, 2002:32–33). As a result, the root causes of established responses to impairment remained unchallenged and "untheorized" (Barnes & Mercer, 2010; Oliver & Barnes, 2012). Undoubtedly, this response is especially disconcerting given the politicization of disability internationally (discussed above) and the profound changes to our understanding of the causes of disablement generated by disabled activists in the UK, which date back to the early 1960s.

In fact, one of the first books to challenge the established "able bodied" orthodoxy on disability was *Stigma: The Experience of Disability* (1966) edited by Paul Hunt. It comprised of twelve personal accounts on living with disability from six disabled women and six disabled men. These were chosen from over 60 responses to Hunt's letter published in several national newspapers and magazines requesting contributions. The aim was to avoid "sentimental autobiography" or a "preoccupation with medical or practical details of a particular affliction."

In his chapter, *A critical condition*, commenting on the experience of disablement, Hunt argued that the "problem of disability lies not only in the impairment or function and its effects on us individually but more importantly on relations with 'normal' people." Disabled people "are set apart from the 'ordinary' in ways that see them posing a direct challenge 'to commonly held social values by appearing 'unfortunate, useless, different and sick''" (Hunt, 1966:146). On discrimination he noted:

> Employers turn away qualified and competent workers simply because they are disabled. Restaurants and pubs give transparent excuses for refusing our custom. Landladies reject disabled lodgers. Parents and relations fight the marriage of a cripple into their family—perhaps with more reason than with a black African, but with many of the same arguments. And it's not hard to see the analogy between a racial ghetto and the institutions where disabled people are put away and given enough care to salve society's conscience. (Hunt, 1966:156)

Following its formation in 1974, UPIAS published its first *Policy Statement* in which it introduced a radical redefinition of disability that breaks the link between disability and impairment:

> What we are interested in, are ways of changing our conditions of life, and thus overcoming the disabilities which are imposed on top of our physical impairments by the way society is organized to exclude us. In our view it is only the impairment that we must accept. (UPIAS, 1974:5)

A year later, four UPIAS delegates met with a corresponding number of delegates from the *Disability Alliance* (DA) to discuss the latter's invitation for UPIAS to join their campaign for a national disability income. As the lack of an income is a symptom and not the cause of disabled people's oppression, they declined the offer. They also explained how the DA's strategy would not address the root cause of disablism with reference to their definition of disablement. From the DA's perspective, impairment was linked to defective limbs or mechanisms of the body, but for UPIAS disability was:

> . . .the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities. (UPIAS, 1976:14)

Subsequently, the restriction to "physical impairments" was dropped to incorporate all physical, sensory, and cognitive impairments. This was due to some conditions, both congenital and acquired, affecting all bodily functions, and in a disablist society, all impairments, whatever their cause, have to a greater or lesser degree negative physical and psychological implications. In addition, impairment-specific labels may well have relevance when accessing appropriate medical and support needs, but they are usually imposed rather than chosen and, therefore, socially and politically divisive (Barnes, 1985).

Thereafter, the UPIAS definition was adopted and adapted by national and international organizations controlled and run by disabled people. These included the BCODP and the DPI. Initially, with respect to linguistic differences across the world, the DPI adopted the terms "disability" and "handicap" (DPI, 1982). A decade later DPI Europe opted instead to use impairment and disability (DPI, 1994b). Moreover, BCODP and DPI's stated policy revolved around the promotion of grass roots organizations and the development of public awareness of disability issues in the struggle for equality. The slogan "nothing about is without us" has been embraced by disabled people's organizations around the world (Charlton, 1998).

Britain's first disability studies course, *The handicapped person in the community*, was conceived and developed by an interdisciplinary team at the *Open University* (OU) in 1975. Vic Finkelstein, a disability activist, member of UPIAS, and social psychologist, was a major influence on the development and delivery of this module. The OU was an appropriate location for this course as it signaled a new and innovative approach to distance learning in university education. In its first year, the course recruited over 1200 students.

As disabled people were increasingly involved in the production of teaching materials, the OU course was updated twice and renamed *The Disabling Society* in 1993 to reflect its wider content before its closure in 1994. The OU team generated a wealth of material that provided the basis for the development of a whole host of disability studies-related courses and professional training schemes at both the undergraduate and postgraduate levels in colleges and universities across the UK (Barnes et al., 2002). This material and other recently published works focusing on disability in Britain including *The Meaning of Disability* (Blaxter, 1976), *Poverty in the United Kingdom* (Townsend, 1979), *The Politics of Mental Handicap* (Ryan & Thomas, 1980), and *Disability: Whose Handicap* (Shearer, 1981) led Mike Oliver, a disabled activist and lecturer, to coin the phrase "social model of disability." This model was his contribution to a collection of five papers edited by a practicing social worker, Jo Campling, entitled *The Handicapped Person: A New Perspective for Social Workers*. Notably, UPIAS had been corresponding with the British Association of Social Workers (BASW) since 1977 (Baldwinson, 2019; 15).

Although not a UPIAS member, Oliver was teaching a module on disablement on social work courses at the University of Kent, whereas Campling's previous work had included *Better Lives for Disabled Women* (1979) and *Images of Ourselves: Women with Disabilities Talking* (1981). Both focused on women's experiences of living with impairment in Britain in the 1970s. Oliver's initial aim was to provide an accessible key to understanding the importance of the UPIAS definition of disability and its implications for policy and practice for social work students. The social model is, therefore, a "heuristic device" or aid to understanding which entails the adoption of the following key principles. First, it is not a denial of the importance or value of appropriate individually medical, re–/habilitative, or educational interventions. Second, it is a deliberate attempt to shift attention away from the functional limitations of individuals onto the problems caused by disabling environments, barriers, and cultures.

In short, the social model of disability is a tool with which to provide insights into the disabling tendencies of modern society in order to generate policies and practices to facilitate their eradication. For advocates, impairment may be a human constant, but "disability" need not and should not be. Although the social model has been linked to several sociological theories of disablement (Priestley, 1998), it is generally associated with materialist accounts (Barnes 2003; Barnes & Mercer 2010; Oliver & Barnes 2012). Moreover, following a presentation to an invited audience at an international 2-day conference entitled *Changing attitudes and the disabled: issues at stake* – funded by the World Rehabilitation Fund in September 1979 – Finkelstein published *Attitudes and Disabled People* (1980), the first materialist account of the creation of disability.

By adopting a three-stage evolutionary model of European history, he argued that disability, the oppression of disabled people, emerged as a direct result of the advent of capitalism and the exclusion of people with impairments from employment during industrialization, mass production, and wage labor. Pre-industrial economies were mainly cottage based and agrarian, and while disabled people were at the foot of the social hierarchy, they were not excluded from economic participation. He suggested that the then emergent post-industrial society would herald the emancipation of disabled people with the aid of new technology and work with others to achieve common goals.

Nevertheless, Finkelstein's analysis has been criticized for its oversimplification and mechanistic, "unscientific" account of social relations within the economy. Namely, he fails to acknowledge the oppression of disabled people prior to the industrialization and the positive role of professionals involved in their care and rehabilitation thereafter (Stubbins, 1979). Also, he was seen as overly optimistic about the role of technology in the empowerment of disabled people. Rather, technology can be both empowering and disempowering for disabled people (Sheldon, 2004). Even so, Finkelstein's monograph stimulated much needed further work on the creation of disability as a social construct.

A particularly important example is Mike Oliver's *The Politics of Disablemen*t (1990). He argued that definitions of disability and other social problems are related to both the economy and associate ideologies and cultures. He explained the rise of liberal utilitarianism, individualism, and the medicalization of impairment came about as result of capitalism's need for a workforce physically and intellectually able for the demands of industrialization. It is not only the changing economy but also the corresponding changing ideologies that precipitated what he calls the "personal tragedy theory of disability" (Oliver, 1990:27). Of particular poignancy, Oliver's argument centered on a) the role of ideology and its reflection in popular culture in the social creation of disability and b) medicalization as social control. More specifically, medical professionals rise to prominence in institutions for "sick and disabled people" (i.e., for those who could not or would not conform to the demands of the new factory-based system). This, in turn, gave rise to notions of the "able-bodied individual" (Oliver, 1990:79).

Likewise, the 1980s witnessed a host of activity on the disability front including the flowering of a burgeoning "disability culture." In 1975 the television program *Link* provided a platform for an emerging disabled group identity and culture which brought to light the unprecedented growth of disabled poets, musicians, artists, comedians, and entertainers. All of which provided stimulus for a range of newsletters and magazines produced by and for disabled people and groups (Morrison & Finkelstein, 1983). Examples included Liberation Network of Disabled Peoples' (LNDP) *In from the Cold* published between 1981 and 1987; *Coalition* the magazine of the Greater *Manchester Coalition of Disabled People* (GMCDP) first published in 1986; and DAIL (Disability Arts in London) the following year.

The first 2-day conference on disability culture, "Supporting the cultural expression of disabled people through the arts," was held at Lancashire College, Chorley, in September 1986 (Finkelstein, 1986). Despite constant funding difficulties, conferences, performance, and exhibitions continued into the early twenty-first century (Barnes & Mercer, 2010:203). 1986 also saw the launch of the first international academic journal for writers and researchers concerned with disability by Mike Oliver and Len Barton. Entitled *Disability, Handicap and Society*, and renamed *Disability and Society* in 1992, its aim was to provide a forum for alternative ways of thinking to the "personal tragedy theory of disability" which had hitherto dominated disability theorizing and policy (Oliver, 1996: 5).

Furthermore, the 1980s witnessed added intensification of the politicization of disability with, for instance, the 1980 publication of the *World Health Organization's* (WHO) first attempt to provide a universally acceptable definition of disablement. Produced by Dr. Philip Wood at the UK's Manchester University, this was a three-stage model like the one used for Britain's first national disability survey in the late 1960s (Harris et al., 1971), whereby "impairment" represented abnormalities of the body and mind, and "disability" is the functional limitations that flow from impairment, while "handicap" was defined as:

> . . .a disadvantage for a given individual, resulting from an impairment or a disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that individual. (WHO, 1980:27–9)

Clearly in contrast to the UPIAS (1974) and DPI (1982) definitions, this model is based on "able-bodied" assumptions of normality and impairment and/or disability and are the main causes of *handicap* as represented as disabled people's economic and social disadvantage (Oliver, 1990).

A year later "Project 81: Consumer directed housing and care" began operations. This project was a scheme developed by inmates at the Le Court Cheshire Home and local authority councilors in Hampshire. It provided indirect payments, in lieu of institutional services, to pay for personal assistants enabling disabled people to live independently in the community (Evans, 1993). In 1985 the *Derbyshire Centre for Integrated Living* (DCIL) produced an operational framework for service support which included the “the seven needs for independent living.” This framework involved information, counseling (peer support and advice), accessible housing, aids and equipment, personal assistance, and transport (Davis, 1990). By 1989, the *Hampshire Centre for Independent Living* (HCIL) added the needs for education, employment, income, and advocacy (Barnes, 1991a).

The growing demand for independent living prompted the British Government in 1988 to set up the *Independent Living Fund* (ILF) with a budget of five million pounds. This fund was distributed by a national agency that provided direct payments (DPs) to disabled individuals to run their own support services. But demand quickly outstripped government estimates, and it was closed to new applicants in 1993. It was replaced with the *Independent Living 1993 Fund*, albeit with restrictions on who could apply and the level of payments that could be made. Thereafter, support was only available with local authority approval as new applicants had to apply to their local authority (LA). Yet, LAs were not compelled to award DPs unlike the ILF (Oliver & Barnes, 1998). All LAs were legislatively required to do was to inform “would be” disabled applicants that they were eligible for DPs: hence access to DPs was commonly referred to as a “postcode lottery” (Priestley et al., 2007). In the interim, the ILF was scrapped in June 2015.

Parallel to the aforementioned developments, the campaign for legislation to outlaw discrimination against disabled people gathered at pace in the 1980s. In 1982, for example, *The Committee on Restrictions Against the Disabled*, CORAD, published its report. Chaired by the disabled activist Peter Large, the committee was set up in 1978. It located the problem of discrimination in inaccessible public buildings, housing, transport, education, and employment. In so doing, it made several recommendations including the need for legislation to secure human rights for disabled people. The newly elected conservative government and the “big disability charities” were unimpressed (Oliver, 1990). That same year the first attempt by a deaf Labour MP, Jack Ashley, to get an anti-discrimination law through Parliament was defeated. Over the next decade, nine other attempts to outlaw discrimination against disabled people were also unsuccessful.

Even so, in 1985, the *Voluntary Organisations for Anti-Discrimination Legislation* (VOADL) was formed. This formation proved to be an uneasy alliance between organizations run by disabled people, like BCODP, and those for disabled people, such as The Spastics Society, run by non-disabled people. As the latter were lukewarm about rights legislation, the campaign for ADL was led by the BCODP. The spread of *Disability Equality Training* (DET), a method of conscience-raising, by BCODP member organizations (Gillespie-Sells & Campbell, 1990) led to a further radicalization of large sections of the disabled population. Yet even then, it was not until the BCODP published *Disabled People in Britain and Discrimination: A Case for anti-discrimination legislation* (1991) that the conservative government and the big charities acknowledged that disablism was a major problem (Oliver & Barnes, 1998).

With funding from the Joseph Rowntree Foundation and Charity Projects, the BCODP research committee under the chair of Mike Oliver commissioned Colin Barnes to provide evidence of the extent of discrimination encountered by disabled people. Barnes, a special school survivor with a congenital visual impairment and disabled parents, had completed a PhD in sociology at the University of Leeds. His undergraduate 17,000-word dissertation “Discrimination against disabled people (causes, meanings and consequences) or the Sociology of Disability” was produced in 1985, and his PhD thesis was published in 1990 under the title *Cabbage Syndrome: The Social Construction of Dependence* (Barnes, 1985, 1990).

Following studies of racism and sexism in Britain, Barnes argued that discrimination against disabled people is “institutionalised in the very fabric of British society and supported by history and culture” (Barnes, 1991a:3). Hence, the BCODP study included a history of disablism in British society and substantive quantitative evidence, based on government statistics of the unequal treatment of disabled people in key areas. These included education, employment, benefits, health and social support services, the built environment, leisure, the media, and politics. It concluded by arguing for a comprehensive anti-discrimination policy and financial support for a nationwide network of organizations of disabled people “as it is these organisations that have put institutional discrimination on to the political agenda, and which are best suited to ensure its eradication” (Barnes, 1991a:232–33).

One thousand summary leaflets were produced and circulated to all BCODP member organizations for distribution (Barnes, 1991b). The findings were subsequently presented, by members of the research team, across Britain and Europe including the first *European Disabled Peoples Parliament*, Brussels, 1993 (DPI, 1994a). Moreover, as Barnes was teaching on a part-time basis in the School of Sociology and Social Policy, University of Leeds, while working on the BCODP project in 1990, the “school” became the home of the BCODP Research Unit. Nevertheless, the BCODP Research Unit operated independently within a wider university-based *Disability Research Unit* (DRU), established in 1992 and later the *Centre for Disability Studies* (CDS) in 1998 until BCODPs collapse in 2006.

By 1991, Mike Oliver ushered in a new approach to researching disablement known as “emancipatory disability research” founded on social model principles that placed disabled people and social model insights central to the research process (DHS, 1992). This approach was adopted by staff within the DRU/CDS who conducted research on a host of disability issues including “Disabling Imagery and the Media” (Barnes, 1992), on independent living and personal assistance, “Making Our Own Choices” (1993), “Cash for Care” with the Institute for Public Policy Research (IPPR) (Zarb & Nadash, 1994), “Measuring Disablement in Society” with GMCDP (Barnes, 1995), and “An Evaluation of Services Led by Disabled People” with the National Centre for independent Living (NCIL) (Barnes et al., 2001).

Likewise, in 1999 CDS was involved in a 2-year project with the Norwegian Association of People with Disabilities and the WHO Disability and Rehabilitation Team’s “Rethinking Care from the Perspectives of Disabled People” (WHO, 2001a, b), whereas in 1995, CDS conducted research on access to the built environment with the University of Malta and the Malta Federation of organizations of persons with disabilities (Prideaux, 2006). In terms of dissemination and teaching, all first-year undergraduate sociology and social policy courses at Leeds had included lectures on disability based on social model insights since 1990; it introduced Britain’s first fullblown disability studies program in 1992. It began with a 30-credit optional course, “An Introduction to Disability Studies,” open to all second- and third-year undergraduates across the university.

A post-graduate (PG) “Diploma/MA in Disability Studies” scheme followed in 1993/4. The PG courses were made available as distance learning options in 1998. These PG courses were open to anyone with a first or second social science degree, comparable academic qualifications, or relevant experience. Crucially, the latter qualifying criterion was especially important in recognition that mainstream education systems are generally not inclusive. And this was particularly evident in most of Britain’s colleges and universities (Harrison et al., 2009). Consequently, it was especially important these courses were open to disabled people wishing to study in higher education. Even though the university has no accurate figures before 1999, the PG disability studies program had attracted over 650 students, including 55 research students. Almost 50% were from outside the UK, and many were disabled (Westmorland, 2020).

The DRU was also a pioneer of online communication and social networking. A disability-research email discussion list server was established by PhD students, Mark Priestley and Emma Stone, in December 1994. It was the first global forum for the exchange of information among disability researchers and activists. It still has over 1300 subscribers. Early conversations focused on definitions and models of disability, drawing contributions from North America, Australia, and Europe as well as the UK (Priestley, 2020). Over the next two decades, the DRU hosted a series of groundbreaking conferences and seminars on disability issues and research for researchers and activists. Examples included “Exploring the Divide: Illness and Disability” (1995), “Doing Disability Research” (1997), “Disability and Development” (1999), and an *Economic and Social Research Council* (ESRC)-funded seminar series on implementing the social model. Topics included theory (2004), policy (2004), and Europe and the majority world (2005). Each of these events yielded an edited collection of articles published by the *Disability Pres*s.

Using previously generated research funding, the *Disability Press* was set up in 1995. It followed several unsuccessful attempts to get an edited collection of papers from the conference, *Exploring the Divide: Illness and Disability,* published by other publishers. From the outset, the main aim of the *Disability Press* was to reach as wide an audience as possible. All prospective authors were asked to avoid, wherever possible, unnecessary academic jargon and terminology, and all publications were produced in several formats. Items published between 1995 and 2000 were available in standard format, a large print version or a Braille copy produced by *The Royal Nation Institute for Blind*’s (RNIB) transcription unit and then housed in the university’s Equalities Unit. Subsequent publications were available in standard format and/or CD on request. The *Disability Press* ceased to operate in 2013.

Eleven of the sixteen *Disability Press* publications are now available to freely download via the *Disability Archive UK*. The archive was set up by the DRU in 1999. Its aim was to provide disabled people, students, and researchers access to the wealth of writings of disability activists, researchers, and allies whose work may no longer be accessible elsewhere. It contains over 600 items including books, research reports, journal articles, and gray literature (Barnes, undated). Indeed, the demand for a disability studies agenda across Europe began in 2002 due to a concern expressed by disabled people's organizations about the lack of European social model research. Thereafter, the European Commission funded a Europe-wide "Academic Network of European Experts" (ANED) in 2007. This involved universities and non-government organizations (NGOs) from 35 countries. It was led by CDS until the UK government's decision to leave the EU in 2017. The network published more than 500 research reports and developed a cross-national database of disability policies and statistics in European countries. It led to a new European journal of disability research and society, *Alter,* and an annual European conference (Priestley, 2020).

Since the turn of the new millennium, there has been a notable growth of interest about disability in universities across the world. There are now disability studies courses and specialist journals, conferences, and seminars in many countries. There are also networks of researchers studying a range of disability-related issues in Europe, the Nordic countries, the USA, and Australia. Similar networks are now appearing across the globe more generally and particularly in Africa, where CDS at Leeds played an integral role in developing disability studies programs in collaboration with Disabled People South Africa (DPSA) and University of Cape Town; South America; and Japan and Taiwan (two influential East Asian locations in which CDS undertook extensive lecture/activist tours between 2008 and 2010) to advocate for the application of studies based upon the social model of disability. All of which have generated an increasingly expansive literature from various perspectives including sociology, philosophy, history, cultural studies, social policy, psychology, and geography (Barnes et al., 2002; Goodley, 2017; Watson & Vehmas, 2019). Importantly, all this activity and greater awareness has raised poignant questions for those working in this area of enquiry. Not least of which is how has the growth of disability studies affected societal responses to people with impairments?

Disability Policy, Disability Studies, and its Future

There is little doubt that the combination of the growth of disability activism and disability studies has been a key factor in the development of policies to address the oppression of disabled people both nationally and internationally. Examples in the UK include the setting up of the ILF (1988), the introduction of the *Disabled Living Allowance* (1992), *The Disability Discrimination Act* (DDA) (1995), and the *Disability Rights Commission* (DRC) (2000). In addition, 1995 saw the then Labour Government Cabinet Office publishes the report *Improving the Life Chances of Disabled People.* By adopting an explicit social model approach, it promised much with reference to policies for education, employment, access, and support for local CIL-type organizations and the setting up of the *Office for Disability Issue*s to oversee their implementation (Cabinet Office, 2005:78). An amendment to the DDA in 2006 introduced the *Disability Equality Duty* (DED). Unlike previous policies, this was a proactive measure mandating all public organizations and institutions to produce plans to make the necessary changes/adaptations to facilitate disabled people's inclusion. These schemes were to be reviewed and amended every 3 years until equality was achieved (DRC, 2006).

Sadly, the rhetoric was not matched by practice. The DDA and DRC were both scrapped in 2006. The DRC was replaced by the *Equality and Human Rights Commission* (EHRC), while the DED was replaced by an *Equality Duty* and the *Equality Act* which was introduced in 2010. Both of which were intended to cover all forms of discrimination. So inevitably disability issues were no longer prioritized. Thenceforth, the leading organizations in the disabled peoples' movement were marginalized. On the other side of the coin, the BCODP's gradual decline began in 1992 when the campaign for ADL was joined by the big charities and compounded by the formation of NCIL and the DRC at the turn of the decade. To compound issues, changing government funding priorities for the voluntary sector meant that these organizations had been submerged into partnerships with the big disability charities. There was also a significant decline in the number of local user-led disability organizations operating across the UK as they were unable to compete with the government-sponsored voluntary sector for local service contracts.

The prospect of an improvement in the life chances of disabled people in the UK was dashed by the coming to power of the conservative government in 2010 (Ryan, 2019) following the global financial crisis that began in the USA in 2007 (Harvey, 2010). Their solution to the economic crisis was a drastic reduction in spending on disability benefits and services. There followed a decade of austerity which demonized disabled people as work shy and benefit scroungers. Newspaper coverage of this issue was reminiscent of that used by the Nazi party in Germany prior to the holocaust in the 1930s. Access to benefits and services was tightened with the introduction of a stringent new disability tests based on the WHO's *International Classification of Functioning, Disability and Health* (ICF) conducted by government-funded private-for-profit agencies and insurance companies (Jolly, 2013:1).

In 2015 the UN conducted research on state-level violations of disabled people's human rights in the UK. In 2017, its findings showed that the conditions for disabled people in Britain were tantamount to a human catastrophe. The UN concluded that the British state was failing in its duties toward its disabled citizens in everything from housing and employment to education and social security (Disability Rights UK, 2019; Ryan, 2019).

Elsewhere, the WHO launched the ICF in Geneva in 2001. Its aim was to provide a universally acceptable language and scientific tools for the measurement of disablement by bringing together the medical and social models of disability into one construct: "the biopsychosocial model of disability." Like its discredited predecessor the ICIDH, it is a concept that has three elements: "impairment," "activity," and "participation." Prominently, though, the terms activity and participation replaced "disability" and "handicap." But unlike the ICIDH, the ICF acknowledges that the entire disablement process is subject to environmental influences.

Nonetheless, it retained the assertion that impairment is the main cause of disabled people's disadvantage in its methodology, language, and title, "the biopsychosocial model of disability." Methodologically, far greater emphasis was given to measuring impairment than activity and participation, whereas the word "disability" was described as a negative term encompassing both a person's limited functioning and disabling barriers but is linked to individuals with the use of the phrase "people with disabilities": thus, the traditional assumption that disability is an individual rather than a societal problem was reaffirmed. In addition, if the environment influences all three elements of the ICF model, then surely the logical title should be the "socio-psycho-biological" (Barnes, 2011; Oliver and Barnes, 2012). Yet that is/was painfully not the case.

Moreover, despite its continued promotion by researchers, the WHO, UN, and World Bank and national governments, there are growing doubts about its usefulness for policy development and implementation. The incidence of disablement within and across nation states is historically, culturally, and situationally variable (Ingstad, 2001; Miles, 2001) and therefore a socio-political issue: an aspect that was sadly missing or deliberately omitted from the ICF model (Barnes & Sheldon, 2010). Therefore, the expressly "apolitical," "scientific" approach of the ICF "does not solve the problem the policy analyst needs to solve" (Bickenbach, 2009:120). Even so, the ICF was used for the WHO and World Bank's *World Report on Disability* (2011). Acclaimed as an "astonishing achievement" because it has the three pivotal insights of single-handedly shifting existing paradigms, making "utterly novel recommendations" and raising "issues never-before considered by people with disabilities" (Bickenbach, 2012:654). As indicated above, however, there was nothing new about the ICF apart from its spurious claims to political neutrality, the supposed novelty of its recommendations or even the issues raised.

What *is* astonishing is the way in which those involved in this report ignored previous attempts to address the problem of disability. The growing international interest in the oppression of disabled people can be traced back to the 1970s and the UN *Declaration of the Rights of Mentally Retarded Persons* (1971) and *the Declaration on the Rights of Disabled Persons* (1975). These declarations were followed by the UN's designation of 1981 as the *International year of Disabled Persons* and the pronouncements of 1983-1992 as the *Decade of Disabled Persons*, *The Asian and Pacific Decade of Disabled Persons* (1993-2002), *The African Decade of Disabled Persons* (2000-2009), and *The Arab Decade of Disabled Persons* (2003-2012) (Barnes and Mercer, 2010:254). Decisively, two further initiatives omitted from the WHO report. First, there was no mention of the UN's *Standard Rules on the Equalisation of Opportunities for People with Disabilities* (UN, 1993) which comprised of 23 rules to facilitate the inclusion of disabled people in all aspects of daily living. Second, the 36 recommendations of the WHO's own 2001 Disability and Rehabilitation Team report, as discussed earlier, were correspondingly and sadly missing.

It is also notable that the ICF has been widely accepted by disability studies scholars and researchers, some of whom were involved in the production of this report as a successor to the "outdated ideology" of the social model of disability (Shakespeare & Watson, 2001). Similarly, the principles of emancipatory disability research have been all but abandoned in favor of more academically acceptable social research methodologies such as critical realism (Watson, 2019). In conjunction with the advent of postmodernism and calls for bringing impairment back in

(Thomas, 1999; Tremaine, 2002), what now passes for disability studies reads more like the sociology of health and illness, rather than the discipline of its founders. Most discussion in today's disability studies takes place in colleges and universities. The majority of those involved write for expensive academic books and journals using language which is often impenetrable to a lay audience and with a content of little relevance beyond the academy, the very opposite of what is needed (Sheldon, 2006; Barnes & Oliver, 2012; Slorach, 2016).

A Final Word

This chapter has demonstrated how the reinterpretation of disability by disabled activists during the 1970s has had an important impact on the perceptions and analysis of disability within and beyond universities and colleges in the UK and the USA. While this is to be welcomed as it signifies a growing recognition of the importance of the issues raised, it should also be treated with some caution. The recent and growing individualization of disability studies within the academy by some disability scholars signifies nothing less than a reaffirmation of traditional academic values and the effective de-politicization of the discipline with little relevance beyond the sterile confines of the university seminar room.

In view of the enormity of the challenges facing disabled people in the coming decades, both nationally and internationally, this begs the question: what's the point of doing it (Barnes & Mercer 2006)? In this respect, it is noticeable that – for reasons still to be explored – the retirement of Colin Barnes in 2014 has left CDS in Leeds bereft of its early dynamic. As mentioned earlier, *Disability Press*, for example, met with its demise in 2013, the CDS "Disability Archive" contains only one informal presentation by Colin Barnes written in 2016 and one CDS briefing by Anna Lawson and Mark Priestley in 2021. Moreover, the groundbreaking CDS "off-site/overseas" Postgraduate Diploma/MA in Disability Studies via Distance Learning for international and/or disabled students has ceased for the foreseeable future, while the various "master" programs on disability have been suspended/abolished since 2020 leaving only one full-time university-based MA in disability studies. There will be no distance learning provision despite the desperate need for such provision arising from the onset of the COVID-19 pandemic.

Clearly, if those who claim to be working in disability studies continue to shy away from the root causes of disablement as defined, promulgated, and instigated by the discipline's founders and subsequent activists, then the struggle for a fairer and more just society and its future must surely be limited if not terminal (Sheldon, 2006). Indeed, the abovementioned decline in critical dissemination of the enlightening possibilities for disabled students (which is clearly becoming apparent) bears ample testament to the premature fatality of both the discipline and future activism before the aims, objectives, and desire to establish true, all-encompassing equality, inclusion, and human rights for disabled people are achieved.

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Part V

Qualitative Research

Qualitative Research: Introduction

24

Paula Campos Pinto and Huhana Hickey

Abstract

Since the 1990s on, we have witnessed an explosion of disability qualitative research, recently boosted by the adoption of the Convention on the Rights of Persons with Disabilities and its call for participation of persons with disabilities in all spheres of life, including research (Flynn et al., *Qualitative Research, 21*(2), 234–250, 2020; Johnson, *British Journal of Learning Disabilities, 37*, 250–256, 2009). Qualitative researchers use a variety of methods to develop deep understandings of how people perceive their social realities and, in consequence, how they act within the social world. From diaries to open-ended questionnaires, from visual documents to participant observation and ethnography, these tools and methods enable rich accounts of the lived experiences of research participants, always complex and multidimensional, in ways that quantitative approaches can never do. This is the reason they are well suited to disability research. The aim of this section is to outline and discuss the epistemological, methodological, ethical, and practical issues that arise from doing qualitative research with persons with disabilities, in a variety of contexts, particularly those who are not part of the majority. In this introduction, after briefly presenting past and current debates on qualitative critical disability methodologies, we present the five chapters that compose this section.

In a 1992 well-known paper, Mike Oliver critiqued the traditional ways of doing disability research as "alienating" and claimed for new "social relations of knowledge production" in disability research. The change required the development of

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what the author termed the emancipatory research paradigm, defined as research that takes account of disability as political rather than individual or social problem, and thus allies with disabled people in their struggles for power and inclusion (Barton, 2006). "Disability is not measles" would also add Marcia Rioux and Michael Bach (1994) to stress the importance of research that examines the social, economic, political, and legal constructions of disability, and thus positions disability as social status that needs to be problematized, instead of cured or eliminated. In these new research agendas, that abandon the singular positivist approaches of the past, "empowerment and reciprocity are central," and qualitative methodologies, although not the only possible research strategy, are "encouraged" (Rioux, 1994, pp.6).

Since the 1990s on, we have thus witnessed an explosion of disability qualitative research, recently boosted by the adoption of the Convention on the Rights of Persons with Disabilities and its call for the participation of persons with disabilities in all spheres of life, including that of research (Flynn et al., 2021; Johnson, 2009). Qualitative researchers use a variety of methods to develop deep understandings of how people perceive their social realities and, in consequence, how they act within the social world. From diaries to open-ended interviews, from visual materials to participant observations and ethnography, these tools and methods enable richer accounts of lived experiences, which are always complex and multidimensional, in ways that quantitative approaches can never do (de Groot et al., 2019). This is the reason they are well suited to disability research. An in the continuing journey to debunk structures of oppression and discrimination in the lives of persons with disabilities, making visible the invisible and audible the voices previously ignored or silenced, methodological innovations have not ceased to emerge in the field, creating new spaces and possibilities for research ownership, while granting "new horizons of theorizing" to disability knowledge production processes (Milner & Frawley, 2018). Inclusive research (Nind, 2017; Walmsley & Johnson, 2003; Walmsley, 2001) is, perhaps, one of the most recent and promising avenues being explored, as are research approaches that challenge dominant North-centered perspectives and engage with Indigenous knowledges and intersectional identities and experiences.

The aim of this section is to outline and discuss the epistemological, methodological, ethical, and practical issues that arise from doing qualitative research with persons with disabilities, in a variety of forms and contexts, particularly those who are not part of the majority.

To accomplish this goal, we invited a diversity of authors from the Global South and North, from different disciplines and different generations. With this diversity of contributors, we sought to bring together multiple perspectives and uses of qualitative methodological approaches that could enrich our exploration of the topic.

Moreover, in line with the goals of the edited volume, we looked for input from researchers with experience in applying qualitative methodologies that are grounded on the social and human rights model. We particularly sought for research that attempts to reach marginalized disability communities, such as Indigenous people, children, girls and women, and persons with intellectual and complex disabilities.

Tristram Ingham, Bernadette Jones, Paula Toko King, Kirsten Smiler, Helena Tuteao, Gabrielle Baker, and Huhana Hickey write a collective piece that explores the potential of Indigenous Māori research epistemologies and methodologies for disability research. Themselves a group of Indigenous Māori researchers with lived experience of disability, the authors introduce us to the Kaupapa Māori Research (KMR) paradigm, "an emancipatory, transformative paradigm" that draws on *pūrākau*, as a form of Māori narrative for storytelling that encapsulates lessons learned, and *wānanga*, as a form of creating knowledge from such stories and narratives. In quite an interesting way, the chapter itself is structured around this narrative framework, illustrating the potential and richness of these methodologies for gathering, sharing, and making sense of Indigenous disability experiences, while also challenging the ableism, institutional racism, and the enduring legacy of colonialism on research, as well as on the lives of disabled Indigenous Māori in Aotearoa New Zealand.

Jorge Manhique and Action Amos' chapter pursue this conversation, from the perspective of research exploring experiences of disability and mental health in the African continent. Two early career researchers, Manhique and Amos draw from their postgraduate research projects to reflect upon the crucial role of language more specifically as a framework that constitutes a significant part of that legacy. Language frames discourses and conceptualizations of disability and therefore in some sense, colonial power is perpetuated in much qualitative research on disability in the Global South when colonial languages are used "as tool to gather data" and "to 'describe' the experience of disabled subjects in journal articles." The authors thus provide examples of strategies they used to disrupt such power and create more inclusive and respectful research practices that further the interests of persons with disabilities, rather than contributing to their continuing oppression and exploitation.

Anne Marie Callus's piece describes the origins and development of inclusive research with persons with intellectual disability, bringing in some examples to illustrate its applications and potential. She delves into some of the challenges involved in doing inclusive research, particularly those related to nondisabled researchers providing adequate support to disabled coresearchers without keeping control over the research project and outcomes. Inscribing inclusive research in the larger paradigm of participatory and emancipatory research, the chapter emphasizes the promising prospects of inclusive research in supporting self-advocacy and the empowerment of persons with disabilities, including those with more complex needs.

Eduarda Pires' chapter, on the Mosaic approach, is the report of such an experience. For her PhD in sociology, Pires is conducting ethnographic research with children with multiple and complex disabilities, in the context of animal-assisted therapy sessions in two school settings in Lisbon, Portugal. The Mosaic approach involves a wide range of qualitative methods and tools (e.g., narratives, photovoice, drawings, paintings and crafts, games, classroom boards, and rag dolls, to mention a few) which taken as a whole enable a more comprehensive understanding of children's lives and experiences as they create spaces for the participation and the voices of children with various levels of abilities and needs. In describing the process of cocreation and application of these methods and tools, Pires discusses the ethical dilemmas encountered and the ways she dealt with them. Her chapter is a rich testimony of the potentiality of qualitative research to challenge notions of vulnerability and dependence, traditionally associated with disability.

Along similar lines, Xuan Thuy Nguyen, Claudia Mitchell, and Tammy Bernasky argue for the use of participatory visual methodologies as transformative approach to social justice. Drawing from a four-year project conducted with girls and women in Vietnam, the authors illustrate how these methods and tools can help transcend critical dialogues about disability rights in contexts of the Global South, while valuing girls and women with disabilities as knowledge producers and making their voice heard.

In short, the five chapters gathered in this section share some common threads. While exploring different approaches to qualitative research, they all join in emphasizing the potential of these methods to address power imbalances in the research process, empower persons with disabilities, including those more marginalized and invisible, and provide a platform for their "unknowing" voices (Milner & Frawley, 2018). Yet, as all authors also alert us, these are not simple processes. Rather they require a constant attitude of openness, self-reflexivity, dialogue, and responsiveness from researchers to tackle the complexities and address the many dilemmas and difficulties qualitative research is fraught with. Only then a transformative scholarship emerges, which truly aligned with human rights principles and practices, and can begin to understand and challenge the structures of oppression and wider relations of power affecting the lives of persons with disabilities in contemporary societies.

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Decolonizing Disability: Indigenous Māori Perspectives of Disability Research in the Modern Era

Tristram Ingham, Bernadette Jones, Paula Toko King, Kirsten Smiler, Helena Tuteao, Gabrielle Baker, and Huhana Hickey

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Abstract

Qualitative research methods show promise in building shared understanding of Indigenous experiences of disability and have the potential to address the power imbalances inherent in Western epistemologies methodologies, particularly (but not exclusively) when it comes to quantitative research.

This chapter explores indigenous Māori research epistemologies and methodologies for disability research in Aotearoa New Zealand. In particular, we highlight the methodologies of pūrākau (storytelling) and wānanga (workshopping) which serve as examples in the richness of Māori-centered understandings that both give prominence to and make sense of Māori experiences. We structure our discourse throughout the chapter within this narrative framework as an exemplar.

The chapter also provides indigenous perspectives from a Global South to identify the critical importance of understanding the ways in which colonization, coloniality, ableism, and racism have intersected in the lived experiences of indigenous disabled tāngata whaikaha Māori/whānau hauā.

Keywords

Qualitative research methodologies · Indigenous disability · Global south · Indigenous narratives · Māori · Pūrākau (story-telling method)

Introduction

> It appears that Māori in the ancient world who had impairment were people with god-like power and god-like status. They were known for the talents that they possessed, not for what they didn't have. As time progressed, this notion appeared to change... (Tikao et al., 2009, p.11)

Pre-colonization, Māori were inclusive of people with lived experience of disability and considered as whānau first or acknowledged as having particular gifts or contributions that added to the lives of the wider collective. However, the experience of colonization of Aotearoa/New Zealand brought with it different ideas and institutions that aggressively privileged Western ontologies and epistemologies (King, 2019). Alongside the proliferation of negative discourses surrounding disability, “Western hospitals” and similar institutional settings were introduced that were used to separate and punish people with lived experience of disability. Modern versions of these institutions based on the Western models of medicine perpetuated the violence to people with disability. They have also served to reinforce the invisibilization of tāngata whaikaha Māori and whānau hauā (Hickey, 2020).

Māori are the Indigenous peoples of Aotearoa (New Zealand) and make up around 16.7 percent of the total population (Stats NZ, 2020). Despite commitments made to Māori through Te Tiriti o Waitangi (The Treaty of Waitangi) in 1840 by the

British Crown, Māori health and disability inequities are "consistent, comprehensive and compelling" (Reid & Robson, 2007, p.3) and have been deemed as a breach of the principles of Te Tiriti o Waitangi by the Waitangi Tribunal (a permanent commission of inquiry) (Waitangi Tribunal, 2019). These inequities impact Māori with lived experience of disability (sometimes described as tāngata whaikaha Māori or whānau haua) although successive governments have failed to collect adequate data to be able to confidently quantify the unjust and unfair differences in outcomes (King, 2019). As a result, this Indigenous group is largely rendered "invisible," when it comes to disability identity discourse, the impacts of colonization, racism, ableism, and within the context of disability supports and legislation (Hickey, 2008, 2020; Hickey & Wilson, 2017; Jaffee & John, 2018; King, 2019; Velarde, 2018).

This chapter chooses to center the narratives of Māori researchers with lived experience of disability around their unique views of qualitative research. Underpinned by a Kaupapa Māori Research (KMR) paradigm, this chapter draws on pūrākau, a form of Māori narrative, and wānanga, a form of knowledge creation, to explore issues of ethically gathering and sharing Indigenous stories and knowledge and advocating for structural changes that address ableism, institutional racism, and the impacts of colonization and coloniality. Given this context, the chapter thus gives prominence to tāngata whaikaha Māori perspectives and interpretation.

The first part of the chapter provides an explanation of pūrakau and wānanga as Indigenous methodologies for sharing Māori knowledge via storytelling within a KMR paradigm. The second part of the chapter provides narrative extracts from the five researchers. This was both a chance for the researchers to share their lived experiences and perspectives in their own words and to build shared knowledge and understanding together. This process both validates and creates Indigenous knowledge and provides rich insights for Indigenous disability research.

Māori Methodologies: Pūrakau and Wānanga

Pūrākau has been described as a form of Māori narrative containing "philosophical thought, epistemological constructs, cultural codes and worldviews" (Lee, 2009, p.1). Researchers have highlighted how pūrākau have not only informed our uniqueness as tāngata whenua, but they are also a fundamental part of our identity (Pihama et al., 2019). The importance of pūrākau is in the teaching and learning of our tamariki and in the role of ancestral storytelling (Pihama et al., 2019). The term "pūrākau" relates to *te pū o te rakau* (the core of the tree) and specifically refers to the *pū* (base) of a *rakau* (tree) (Lee-Morgan, 2019). Pūrākau is a means by which "stories of the histories and traditions of *whānau*, *hapū*, and *iwi*, (families, subtribes, and tribes) were shared inter-generationally, including the formation of personal or tribal relationships, alliances, struggles and battles" (Pihama et al., 2019 p.140). Māori narratives have been described as containing life lessons with "deep, often hidden wisdoms that establish tikanga or principles that guide and shape behaviour" (Lawson-Te Aho 2013, p.64). Pūrākau are viewed by Māori as "fundamental to our sustenance and growth, as soil and water are to trees" (Lee-Morgan 2019 p.151).

As a Kaupapa Māori theory and methodology, pūrākau has been used in many ways. Pūrākau have informed "*kōrero ingoa* (naming stories) which are the meanings behind our names; how we choose, give, receive, change, and uphold our names throughout our lives" (Seed-Pihama, 2019 p.108). Pūrākau have been considered the ultimate paradigm for the conceptualization of mokopuna sovereignty rights to health and well-being in Aotearoa (King et al., 2018). Pūrākau have played a pivotal role in the recovering of mana wāhine stories providing "ritual maps that offer instructions toward inner-transformation and healing" (Murphy 2019 p.34). The ways in which tikanga and mātauranga are channeled in modern-day Māori contexts to provide safe and enriched approaches to childrearing and whānau well-being has been attributed directly to the use of pūrākau (Pihama et al., 2019). Pūrākau have also been used as a therapeutic approach to healing within the context of mental health and well-being, providing a medium through which whānau and individual challenges can be negotiated without using the vocabulary of psychiatry (Kōpua et al., 2019; Rangihuna et al., 2018). Stories are shared with tāngata whaiora and whānau via wānanga, contextualizing the challenges they face within their own lived experiences and emphasizing the transformational power of pūrākau through the privileging of Māori voices (Cherrington, 2003; Rangihuna et al., 2018).

Consistent with a KMR theoretical and methodological focus on politicized, culturally responsive, and transformative research, the authors recognize and acknowledge pūrākau as intrinsically pedagogical. In the embracing of Māori methodologies, pūrākau is the approach taken in this chapter to privilege voices of Māori with lived experience of disability within the context of wānanga as a process of creating knowledge. The Māori concept of wānanga emphasizes that, within Te Ao Māori knowledge is perceived to pre-exist in the world, rather than occur from the result of human output:

> The goal of the knowledge journey, therefore, is not so much the gathering of discrete pieces of humanly created knowledge but rather the 'cleansing of the lens of perception' whereby the world itself seems to speak (kōrero) to those who have the commitment and willingness to hear. . .knowledge and understanding arises in the consciousness of the individual contiguous with the progressive revelation of depth in the world. (Royal, 2011, p.5)

Just as our ancestors made sense of their experiential realities through the sharing of pūrākau (Pihama et al., 2019), so do the researchers who contribute their narratives and storytelling to the wānanga documented in this chapter. The researchers who share their voices in the next section are from a range of professional backgrounds, disciplines, and cultural origins, and all have lived experience of disability. They explore their legitimate perspectives of the challenges they face within an ableist and colonized society. Through the processes of pūrākau within the wānanga, each has undergone a creative process of the mind, resulting in a shift in awareness within themselves:

> *Ko ngā hua o te wānanga ko te aroha, ko te māramatanga.*
> The fruits of wānanga are *aroha* and *māramatanga*. (Royal, 2011, p.19)

Kaupapa (Purpose): Perspectives of Indigenous Researchers with Lived Experience of Disability

The following narratives are from five Māori researchers with lived experience of disability (refer to the appendix for their positioning) with four overarching themes providing an intersectional analysis of current and future disability research. These are 1) Tino rangatiratanga/self-determination over qualitative research, storytelling and sense making; 2) qualitative research and Māori ontologies and epistemologies, power, context, and connection; 3) challenges of qualitative disability research, paradigm clashes, status, barriers, institutional racism, and ethical issues; and 4) strengthening Indigenous disability research.

Tino Rangatiratanga/Self-Determination Over Qualitative Research: Storytelling and Sense Making

Huhana: I spent 17 years at Waikato University. In 2004, I started my research with Linda Waimarie Nikora and Ngāhuia Te Awekōtuku where we did disability support service research with Māori (Nikora et al., 2004). The recommendations of that research were simple – Māori should have tino rangatiratanga over their services. Research before and after this made similar recommendations, yet policy decision-makers have ignored the findings. I have been involved in research ever since. I have worked in qualitative more than quantitative research, mainly because I like the pūrākau or the story-telling aspect of qualitative approaches. In my PhD, I conducted interviews about pre-colonial views of Māori and disability (Hickey, 2008). I reached saturation quite quickly because they all said the same thing: “We did not segregate our whānau. We did not label them. We did not marginalise them. They were a part of our whānau.” It was that simple. From there, I have been dedicated to building a better understanding of who we are from a Māori perspective as [whānau] hauā, taking an empowerment view. Western ideology around [disability] identity is very deficit based, but Māori do not see us in that same way. Or rather, they didn’t. There’s a mixture of pre-colonial knowledge and bible knowledge which has impacted a lot of the knowledge around identity for disabled Māori. In my work I have been trying to expose, unravel, understand, and amend our thinking.

Kirsten: My long-term goal was not necessarily to become a researcher or academic, rather I wanted to do a lot of unpicking of what life is like at the “intersections.” I had a unique childhood; New Zealand Sign Language (NZSL) was my first and home language. In hindsight, it was a valuable experience; it gave us a differing orientation to the world. For me NZSL and Deaf culture was, and is, a way of being that belongs to my family and whānau. When I was younger NZSL was considered a bit “fringe,” not recognized by the speaking majority as a language; our family and whānau experienced the wider societal prejudices and discrimination as a consequence. It was a confusing place to grow up in. Society suggested we should be embarrassed by our differences, and yet my mother and her brother were proud of their language, community, and families. Growing up, I saw a societal shift in the status of NZSL especially after the NZSL dictionary affirmed the culture and language of our family, whānau, and community. Through their experiences, I learned the power of research, and how research can deeply impact people's lives across generations. As young children we were reminded about [how] our hearing privileges us and provides [us with] responsibilities to act as allies, to provoke, challenge, and seek justice. I wanted to unpick all these experiences more.

Up until my post-graduate study, I didn't see my experiences or the experiences of my family and whānau, reflected in any literature, nor could I find many people who could speak to that kaupapa with much authority, other than people from within the community who weren't in academic spaces, despite being very knowledgeable. It was sad that here were these really valuable and beautiful orators and philosophers, very intellectual people, whose knowledge was really just for those who understood the [sign] language. It was a real treasure, and we really needed to find ways for other people to access this wonderful knowledge. Like Huhana, I like the pūrākau aspect. I value NZSL, and qualitative research allows for the natural expression of perspectives and understandings which aren't necessarily represented in academia. NZSL is embodied in the moment (rather than in text); it's a dynamic experience. That's valuable to me and a main reason why I like qualitative research.

Helena: Having lived experience of disability is what attracts me to qualitative research. I do not have professional experience in qualitative research, but I am attracted to being a part of co-design and co-creation as a form of participatory research. That is what I am really attracted to: using stories, storytelling, collaboration, and co-creation.

Tristram: I started as an academic researcher working on a large cohort study, conducting quantitative epidemiological surveys and multicenter randomized controlled clinical trials (RCT). What I found in that context is that pure quantitative research, while it was good in many respects, really was not able to unpick the real-life barriers whānau were facing. That generated a strong interest and understanding of individual experiences and perceptions, and a move into more qualitative research, which is where I formed partnership with qualitative colleagues who I got to know quite well. For me, there are several aspects around qualitative research that are important. One is that it allows us to dive into intersectionality. The cumulative and differential impact of ethnic inequities and chronic health conditions and disability are related inequities; and qualitative research can put these complex paradigms into a true sociocultural context. This is essential for translating research into effective policy.

Bernadette: I started in quantitative research with my first research project and questioned why so few Māori were enrolled in the research; I wanted to know why we had not engaged with Māori researchers and why we had not engaged with Māori communities. There were even fewer tāngata whaikaha Māori involved in research, despite the project being about chronic respiratory conditions, which are in themselves disabling. I expressed my interest in designing our own qualitative studies, partnering with Māori communities, and finding out what Māori communities really wanted. I changed to qualitative research initially because the quantitative survey questions that existed were not validated for Māori. We found Māori participants did not understand a lot of the questions in the surveys, and largely these surveys only measured some of the gaps or inequities. They didn't provide explanations for why these inequities persisted or how the inequities could be eliminated. For Māori disability research, you have to start at the beginning and find out from tāngata whaikaha Māori themselves; you have to explore what they think the real issues are and what the solutions might be. This community perspective was in stark contrast to how we had been doing our non-Māori quantitative research.

Qualitative Research and Māori Ontologies and Epistemologies: Power, Context, and Connection

Huhana: We are told that without statistical analysis, research is not valid. But qualitative is broader than that. It's more personal. You can delve into history. It sits beautifully with Indigenous-based methodologies because you go beyond the evidence of data alone. If you want to know if something is black, brown, or white, quantitative data alone wont necessarily help, whereas in Indigenous methodology reflects that colour can be multiple shades. We look at things beyond what we see in often oversimplified data.

How do we know if Māori are accessing disability support services to the right level, and what is happening for those Māori who miss out on the supports? You can't find that out in quantitative data alone, you can't explore ideas further. With qualitative you can, and with pūrākau you can. You could find several rationales as to why Māori access health or disability services and importantly why they have not. That's the key difference for me around qualitative research; it sits within our oral histories. It sits beautifully within who we are as Indigenous peoples. We look beyond the basic evidence and delve into everything else that makes that person who they are.

Currently [for disability], we don't have an inclusive language. The only language is an impairment deficit-based language. If we had an empowerment-based model, like some Indigenous Māori researchers do, we [would] use terms such as "whānau hauā," "tāngata whaikaha," or "whānau whaikaha," and we know what we're talking about. Maaka Tibble once told me, there were over 200 words to describe blindness. They described their disability in a pūrākau, and everyone had a different experience of how they became blind. You might have had your eyes gouged out in a war and you'd have different words if you were born blind, or if you went blind with old age. Māori traditionally saw their impairment as a story and would talk about how they acquired [it]. "Ngāti Kāpō" is an umbrella term; it does not describe blindness to the fullness of all the blind Māori out there. "Whānau hauā" is an umbrella term to describe general disability, but within that people can self-identify. We coined a phrase "waka tūru" (moving chair), for people [with lived experience of] physical disability – a descriptive term rather than a literal translation. Indigenous people have the ability and the right to self-identify. I'm not just Indigenous but I'm also Māori, I'm disabled, I'm takatāpui, I'm a wahine. Non--Māori might say "I'm not Indigenous but I'm a wahine, I'm disabled and I'm Irish, and I'm straight."

I was born a month early and had difficulty with my lungs, but I survived, but I spent my childhood coughing up blood and I had chronic bronchitis. We know those terms today; they're the medical terms, but in the old days we would have talked about this baby came early, she was a taonga because she survived, and she survived with weak lungs. But then her journey is she became a runner, or she became this or that. It's all about the storytelling describing your abilities and who you are; it's not about your impairments. It didn't box you into an identity that was going to constrain and limit you.

Helena: My entry into qualitative research is in being part of a [community] co-design process. The leadership group was made up of equal numbers of disabled people, family, whānau, service providers, and local officials. But while it was equal in number of everybody sitting around the table, it was inequitable in terms of the barriers to participation and engagement that disabled people around the table had and also bearing in mind that they were the less resourced also. Disabled people needed resourcing to be able to contribute in a meaningful way.

The membership of the group was eventually changed to shift the balance toward disabled people and have fewer service providers involved. Processes were improved too, for example, giving tāngata whaikaha Māori the option of speaking first.

When we began to co-design the project, we knew that there were Māori who needed services but did not engage in the current system. We also knew there needed to be healing because of the traumatic process of us as Māori being divided by a deficit medical model and its system. The community had been fragmented over time by being separated and siloed into different impairment types because of how services were structured. We knew that we couldn't just go into the community and say, "Well, can you tell us what your good life looks like?". We had to start with healing. The good thing about co-design is that everybody is in the room. There are very different perspectives from lived experience. Officials and the service providers get to hear stories of lived experience as part of the process. These aspects of qualitative research generally and co-design specifically are very powerful.

Kirsten: Another strength of qualitative research is as basic as being able to use your language. Especially when your language is not represented in any academic texts, or you just don't see it in any media or public occasions. When you do qualitative research, there's a bit of a social performance that goes on. I think that in itself is a really valuable experience: just having a discussion in your first language embodying and exploring ideas. It is powerful and affirming for me as a researcher who wants to use NZSL, but also for the people I have had the privilege learning from. Through the process of people sharing knowledge, experiences, and understandings in their first language, you see the mana of language, affirming the connection between communities who use that language.

One challenge for me, as a NZSL user wanting to acknowledge the mana of the language, has been when it came time to "handle data." Qualitative filmed interviews in NZSL are often translated into a written language (usually English), and then we often rehandle the data in qualitative data analysis systems such as NVivo. Deducting or inducting from data using your memory or repeatedly watching recordings of visual language and then handling and triangulating this with the written translated text is a laborious and complex task. It raises questions about how we might dilute or misrepresent the content by altering the form of "data." There are also definitely tensions around how we should represent the qualitative data, so it can be understood by those who might need to be informed about a community's reality and perspective while meeting a community's expectations and being "visible" in the process.

Bernadette: I made the shift over to qualitative methodologies because the quantitative research was very much informed by a Western paradigm. It didn't allow for a Māori lens or influence. I'm thinking about a community partnership project where we went out to a local marae and started from the beginning by asking the local Māori kaimahi to tell us what issues the community identified as priorities and how they wanted this project to be designed and run. The qualitative approach allowed for that flexibility. We were also able to adapt the study as we went. I was taken out with the kaimahi in the area and shown how they work with whānau. Allowing that project to be shaped by the tāngata whaikaha Māori community permitted more inclusion of processes that were familiar to whānau, including tikanga embedded approaches led by whānau. It gave them the options of where they wanted interviews either in their homes, or on a marae, or a place of their choosing. "Mainstream" academic institutions were not "whānau friendly," which is one of the reasons Māori said research wasn't very accessible. Applying a Kaupapa Māori Research lens to this qualitative research made it more inclusive. For us, inclusion of key kupu te reo (Māori words) made participation in the research more familiar along with other cultural aspects such as providing space for karakia (prayer) and shared kai (food).

I think after nearly 20 years of research, I see the in-depth qualitative aspect as essential to inform robust quantitative research or any type of research. A mixed-method approach for tāngata whaikaha Māori combining qualitative research, followed by quantitative methodology, also is very effective. But you must do the qualitative part first, and you get the right questions from a tāngata whaikaha Māori perspective, so the survey questions are correct.

Tristram: In Aotearoa, the fundamental and overarching constitutional framework we collectively live, and work, under is that of Te Tiriti o Waitangi (Te Tiriti). This needs to shape and guide, certainly much more than it currently does in "mainstream" New Zealand, our approach to healthcare, service design and delivery, policy development, and establishing/maintaining genuine community partnerships. Considerable work has been done in Aotearoa about building a Kaupapa Māori Research paradigm (Smith, 2012). It started in education but has really moved across into health and other aspects of medicine and social sciences. It's really an emancipatory transformative paradigm. There's a lot of relevance of that principle-based paradigm that aligns really well with the intents of both the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the Declaration on the Rights of Indigenous Peoples (UNDRIP), insofar as both prioritize the individual or collective rights of individuals or whānau and the requirement for the system to partner with those groups in determining the way that services and community functions are undertaken. I think exactly the same is true in research, as in Te Tiriti, where tino rangatiratanga, or self-determination, is a critically important part of the research process.

What I really like is the richness of the qualitative aspects, particularly when using a Kaupapa Māori paradigm which is really principle based. It's been said that the journey is as important as the destination. As an emancipatory paradigm, it's important that the research itself is not taking away from whānau, that it is a positive contribution, one where the journey (the process and participation) is as important as the destination (the research outputs). So, qualitative interview styles, and other qualitative methodologies that we have used (e.g., pūrākau, phenomenology, interpretive phenomenology, photovoice), really allow whānau to self-define what is of importance and relevance for them and to steer the conversation in ways that makes sense to them. Even from a purely health literacy perspective, it makes sense to scaffold the questioning based on the understanding of the person.

We have seen this recently with trying to design quantitative questionnaires for disability, where we may use the Washington Group Short Set questions as a very rough proxy for impairment, but those questions do not cover the sociocultural context for disability and the process of disablement (Stats NZ, 2017). They certainly do not cover the intersectionality of culture and disability – where racism and ableism can have parallel and summative disadvantage. There is no single established kupu or word that is universally recognized and understood as representing disability. Even in English, it means different things to different people. In Te Ao Māori disability is not a concept that is natural to the population. It comes from a Western deficit paradigm and one that does not sit well for from a Māori world view.

That really alters the likelihood of someone affiliating with the term. We know from research, for tāngata whaikaha Māori or whatever term you use, on the whole we identify as Māori first, disabled second – if at all! It becomes very difficult to generate question sets that really understand and can demarcate the differences in disability experience, cultural paradigm, and world view of people that could represent the diaspora of lived experience. Those kinds of issues make it very difficult to design and validate quantitative questions; and yet these are areas where qualitative research can really have a rich kōrero around. The process of going through that kōrero can itself be a way of healing. A number of whānau have told us that actually just having a safe space to be heard and to feel listened to was in itself a positive intervention for them on that journey to healing.

Kirsten: On the topic of terms or kupu, usually we are told we need to frame research questions by asking “What does the literature say?”. Academic processes typically demand we investigate academic literature to consider the validity of processes, evidence, findings, and discussions – all of which is presented in written English and sometimes te reo Māori. For me this is challenging because sometimes I understand research questions and problems as they are expressed to me by NZSL users, and then I have to frame them using a literature base which is all written in English. I am constantly triangulating and synthesizing across languages and thinking mindfully about how to engage with people who 1) don't engage with that literature base and 2) don’t have shared terminology. So, as a researcher, I’ve had to go into these community spaces and think, “What is the question and how do I engage and frame or try and stimulate discussion?” Because they [Turi] don’t understand the issues and the problems in the same way that people who are writing the literature do.

That’s been really challenging to navigate but also rewarding, because through that process, NZSL users often guided me in building understanding. I also often find that if you give space to understanding issues from a NZSL perspective, solutions to problems are embedded in the language. The example I often use to people is the term “intervention.” When I was doing my PhD thesis looking at “early intervention” (Smiler, 2014), I had to use that term because it was what was written in the academic literature, but it was in sharp contrast to terms used by NZSL users, who often told me it was offensive.

Challenges of Qualitative Disability Research: Paradigm Clashes, Status, Barriers, Institutional Racism, and Ethical Issues

Bernadette: There are huge challenges when trying to get any disability research funded. The funding model has basically been developed and built on a biomedical, ableist, research paradigm exclusive of tāngata whaikaha Māori methodologies. Qualitative research has often been seen as a soft option for collection of data and as an evidence base for innovation and translational research. Mātauranga Māori (Māori knowledge) hasn’t been valued by non-Māori until more recently. Many funders don’t fund disability research, and often “disabled” Indigenous researchers are not valued or supported compared to others. Institutional racism was the basis for most of the research that I was first involved with. It was essentially racist in its design and non-inclusive of Indigenous disability perspectives. It’s only in recent years and with increased willingness from non-Māori colleagues that some of those racist approaches and biases have been slowly recognized and replaced.

The perceived status of qualitative research also has an impact on us beyond funding. “Gold standard” research is still largely seen as the RCT methodologies. This is what largely matters to funders and policymakers. For tāngata whaikaha Māori, RCTs are not the only approach that we can use. Government agencies still value the hard data collection, but as we have seen with the last census, those results were catastrophic and largely unusable (Kukutai & Cormack, 2019).

Huhana: What Bernadette says is spot on – the real lack of support. This is actually Western ideology versus Indigenous ideology – it’s that simple. There’s no flexibility in funding to really allow for a cultural lens fully. When I did my applications around my post-doc[toral research], ironically the university expected me to provide biscuits and tea, but not a meal. You don’t turn up with a packet of biscuits to a Māori household and expect that to be adequate. That’s not creating conditions for engagement, nor is it recognizing and valuing their time, their expertise, and their information. I insisted and won the right to take kai to every interview for a meal. That was me saying that I value you as a whānau and we’ll talk over a meal. That brought a lot of buy-in. It wasn't an inducement – which is what the Pākehā call it; it was manaakitanga and whakawhanaungatanga; and those are concepts around mātauranga Māori, something that our Pākehā institutions don't recognize.

There's also the lack of support for disabled academics to do the job, but we are expected within a university environment to fit within their ableist parameters. As a disabled academic I failed to fit and that's why I didn't get tenure and that is simply because they would not accommodate anything, other than provide a lift and make sure I had an accessible loo [toilet]. There's no real accommodation if you are disabled or if you're Indigenous when it comes to Pākehā institutions and funders understanding that there's specific ways you work with Māori and there's specific ways you don't. You must recognize those ways. We are having to accommodate under a Western lens when we are trying to explore Indigenous research topics.

Helena: What is happening with the new [New Zealand Health and Disability] System Transformation (Ministry of Health, 2021) is again trying to fit Māori into the box. What they [government] are doing is transforming a Western system. I wonder about how transformative the system is going to be for Māori. Also, given the outreach and the knowledge our communities, that our tūhono Māori (connectors) already have and how much time that took. Māori are just not accommodated. I think that is a real limitation when we are looking at "system transformation." I wonder where in all of this the partnership aspect is. It also feels like we spend time continually educating government agencies, who are meant to be implementing this, when they don't have the knowledge to be able to do it effectively.

Kirsten: I also want to talk about professional development and the relationship between major funders and training institutions. They both have a really important role developing qualitative researchers in this space. [Funders] have a lot of work to do in terms of supporting and resourcing these careers. I would really like to see [them] do something substantial or dramatically different in their commitment to this space. I think without them and their commitment, we won't see it grow in the way that we need to.

Tristram: I have encountered pragmatic and ethical issues. Firstly, through my academic experience particularly societal and/or academic and funding biases that exist. I have sat on several assessing committees for health research funding agencies and written a number of grant funding applications myself. I can see that it's not a limitation inherently of the research approach, but one that often makes it harder to get funded. There tends to be biases against genuine co-design, partnerships, and community participatory research in academic research practice. Whanaungatanga (relationships) that researchers have with communities take a long time to build and that genuine consultation and engagement takes resourcing which is never covered by the grant funding (as to be genuine it must predate the application) and is seldom directly supported or recognized by the research institution. There is a significant opportunity cost for Māori and tāngata whaikaha Māori communities who engage with researchers – and these communities frequently lack sustainable resourcing and are already overstretched. Furthermore, that engagement and genuine interest rightly builds an expectation on researchers to deliver to the community aspiration with respect to funding bids, despite not having control of funding success. I hate going back to our communities and apologizing for not having been able to secure the funding we sought despite good science and genuine community need. It feels to many like a further process of racist or ableist trauma.

Meanwhile, we see colleagues in other research areas who do not invest the same amount of time these community relationships or translational activities and instead prioritize polishing their application or push "sexy scientific questions" over genuine community need or favour high-impact international over local or open access publications and community presentations be rewarded at all stages of the current system. Secondly, in terms of crafting funding applications to oversubscribed, Western-dominated, non-disability aware research funding agencies, we and colleagues have experienced difficulty getting grant assessing panels to accept the perceived "risks" of co-design projects insofar as the implicit tension that exists between prescribing enough of the research processes and outcomes to permit evaluation for scientific rigor while retaining space to intentionally co-construct the research agenda with those community partners as the research unfolds. There is an inherent bias toward known risks versus unknown risks. Funders are gradually getting more sophisticated in being able to understand that, but as said, there is a lot of room still to improve there. I want to challenge research to push into translational activities. In my experience, I found that qualitative research is good for highlighting the issue, generating media interest, and putting a face to an issue. But it does struggle sometimes with policy or decision-makers to leverage specific policy changes. It comes across as a barrier when policymakers struggle to see the scale of the issue in relation to evidence that's presented in a qualitative manner. Frequent discussions around generalizability come up, even though we recognize that qualitative research does not aim to be generalized.

The other issues I wanted to talk about are the practical or logistic ones. KMR and a lot of community-based research involving Māori tends to favor kanohi-ki-te-kanohi (face-to-face). As a researcher with a lived experience of disability, and a power wheelchair user, the logistics and accessibility of field work is difficult. There is very limited support for disabled academics to have their access and reasonable accommodation needs met to be able to undertake research. It's not something that is on the radar of academic institutions. Although we have moved through the COVID-19 pandemic to embracing digital technology, significant inequities exist for tāngata whaikaha Māori in access to digital resources and digital technology and adaptive technology. Even the assessments to actually use technology, even if it were physically and financially available to many, are not funded in Aotearoa – so many tāngata whaikaha Māori have real difficulty accessing adaptive technologies. I think the digital divide is an increasingly important barrier in this space.

Strengthening Indigenous Disability Research

Bernadette: I would like to see direct efforts from funders to support capacity and capability of tāngata whaikaha Māori, whānau hauā, and whānau whaikaha Māori as researchers in their own right. We need resourcing to apply to the major research funders, as only very small amounts of funding go to Māori disability research. I note that tāngata whaikaha Māori expertise is generally missing on the research assessing committees, so the issues are not well understood by people making the funding decisions. I have always seen one of the strengths of qualitative research for tāngata whaikaha Māori as being a transformative methodology. We have been able to build on the principles of KMR [but] KMR hasn't been designed by, nor has it particularly focused on, tāngata whaikaha Māori, and I think there's still some gaps and quite a lot that needs to be done to include tāngata whaikaha Māori paradigms.

Māori with [lived experience of] disability may to some extent internalize being disabled, just as some of us have internalized racism because of the influences of a racist society affecting our internal thinking that we're not good enough. While there are some Māori researchers with lived experience of disability, there's not a large body of these researchers who have had the opportunities, capacity, or the support to evolve KMR methodologies using a tāngata whaikaha Māori lens. We need to support Māori in developing and disseminating some of these methodologies. There's a big gap there, and we need to build on work that tāngata whaikaha Māori researchers have done.

Kirsten: There needs to be changes to how funding applications are assessed. A while ago [New Zealand Health Research Council], processes changed and applicants were asked to respond specifically around the impacts of their work for Māori and research relationships with Māori communities and so on. Assessing committees were given clear guidelines on how to respond to this, and non-Māori researchers quickly learned that they had to critically engage with Māori in order to respond to commitments outlined in Te Tiriti, but also they simply wanted to be successful in gaining funding. These changes ought to be created to give effect to the rights of disabled people and in order to provide the scholarship needed to develop the health and disability sector. This is an urgently needed action point: fund more people with lived experience of disability to develop work and lead in this space. More specifically, turning to language again, I have always wanted to see NZSL (or signed languages in general) and te reo Māori visible in academic literature bases and forums. It is as basic as that: we need to see and experience our knowledge in these spaces. That's one thing that I would like to see happen in my lifetime.

Helena: I also think there should be more room for tāngata whaikaha Māori to be researchers. In Aotearoa, we are also considering changes to the structure of the health and disability system which includes some kind of Māori Health Authority to give Māori more control in decision-making and policy. This Māori Health Authority structure needs to play more of a part in making space for tāngata whaikaha Māori too and ensuring disability input from the beginning. For tāngata whaikaha Māori, there needs to be clarification or delineation between health and disability. We definitely need more research, and it needs to be done by tāngata whaikaha Māori, and also in terms of capacity and capability development, we need another lens put over it, because the current system is all about disabled people Māori – tāngata whaikaha Māori – being recipients rather than leaders. My belief is that Te Ao Māori is inclusive of everybody. I think that everybody would benefit from research, which kind of begins in this space, from the knowledge that Te Ao Māori is inclusive of everybody.

Tristram: I really tautoko (support) the points made by everyone on strengthening qualitative research. I come back to intersectionality and tāngata whaikaha Māori. There are international and national obligations toward disabled people and Māori, but there is almost complete invisibility of that intersection, which we call tāngata whaikaha Māori. Within disability rights discourse, Māori are seen as a "minority" issue. Within Indigenous rights discourse, disability is seen as a "minority" issue. Even where there is acknowledgment of this intersection, the scale of issues is not well understood in part because of lack of data and research. In my view, this is unacceptable – because the obligations are very clear. Article 31 of the UNCRPD talks about the requirement for state parties to have research evidence and statistics on disabled people. I guess you would say that the UNDRIP doesn't have such a clear parallel; Article 15 of UNDRIP talks about Indigenous peoples having the right to their own ways of learning and knowledge systems, which I think is relevant here. So, I would like to see greater recognition of the intersectionality of these fields.

I would also like to endorse earlier comments about more genuine capacity development. This necessarily means development of researchers outside the academy. Academic biases against community leaders and people with lived experience of disability mean they are not deemed to be researchers in their own right. Their contributions are not valued because they cannot describe it on an academic curriculum vitae. It saddens me to hear of Māori community leaders not considering themselves researchers in the pure sense because of that Western paradigm that conforms to an academic model. I think the problem with our system to date is that it has not really embraced and recognized the genuine value of communities.

Another thing to address going forward is ensuring partnership in participatory research. To genuinely undertake co-design is to come to the table as equals. Yet, our frameworks in academia, in the health [and disability] system and in government, do not really allow for genuine partnership and genuine shared decision-making. It is clearly a power imbalance and that comes from historic inequities in capacity development. I would really like to see capacity development, for communities to prioritize their own research agendas and seek out academics rather than the other way around. Finally, I think there is a real need for both policymakers and health [and disability] system designers to build evaluation into system design and implementation, in the implementation of all policies and interventions, to a far greater extent. And, that would build a space for qualitative research, as an essential component of evaluation, which seeks to understand implementation barriers and organizational issues when implementing policies.

Huhana: Intersectionality is a very big part of our identity because we are forced into these labels and stereotypes, when in Te Ao Māori we live on a continuum. Yet, in reality, everyone lives in a continuum. Western science and ideology and thinking tells us, however, that we must be compartmentalized. But if we were to look pre-colonially, there's just some fantastic stories out there, around our Mana Turi, Ngāti Kāpō, our Waka Tūru whānau: our whole whānau. They were leaders. They were gods. Going forward, universities need to stop seeing us as being part of the problem and create safe and supportive space to employ us. What we do is great as community researchers, but the question now and into the future is how do we survive and thrive in that toxic environment known as a university? We can't do it without each other. Interdependency, co-designing, intersectionality, and all of those things are part of who we are.

My last point is really for disabled Māori researchers in the community. Never underestimate the value of what you do in the community. Even if you are not part of an academic institution or an "academic," your connections, your relationships are all very much a part of what makes your research valuable, because you get in where a lot of academics cannot even think about getting to.

Conclusion

This chapter serves as an example of how pūrākau and wānanga can be used to explore the richness of Māori-centered understandings to both give prominence to and make sense of Māori experiences. While each researcher participating in the wānanga came with their own lived experiences of disability, and their own experiences of qualitative research, the layering of their pūrākau within the context of wānanga allowed for new knowledge to emerge. Qualitative research methods show promise in building shared understanding of Indigenous experiences of disability and has the potential to address the power imbalances inherent in Western epistemologies methodologies, particularly (but not exclusively) when it comes to quantitative research. This chapter also highlights the critical importance of understanding the ways in which colonization, coloniality, ableism, and racism have intersected in the lived experiences of tāngata whaikaha Māori/whānau hauā. These intersections have also impacted the languages that are used and considered "vaild" and "credible" in a research context and those that have been invisibilized (including NZSL and te reo Māori). Additionally, practical logistics and the challenges faced in the context of tāngata whaikaha Māori/whānau hauā led qualitative research, including a lack of dedicated funding have been emphasized. Genuine partnerships involving equitable funding from funders, universities, and other research institutes are critical to creating the space for Māori and other Indigenous researchers with lived experience of disability to self-determine their own research agendas and to connect with their own ontologies, epistemologies, and methodologies, in turn opening up new ways of knowledge creation, making, and meaning.

> Any approach is valid if it's aligning with tikanga Māori and its working, as long as the right people are leading it. We don't want to be constrained by Western academic methodologies. We do it because it's culturally acceptable for Māori. (Bernadette)

Glossary of Māori Words

Aotearoa	the original and indigenous Māori name for New Zealand
Aroha	love, compassion, empathy
Atua	deity
Awa	river
Hapū	kinship group, sub-tribe, sub-nation, to be pregnant
Hauora	healthy, well
Hine-nui-te-pō	name of a deity
Iwi	extended kinship group, tribe, nation, people, bone
Ingoa	name
Kai	food, meal
Kaimahi	worker
Kanohi-ki-te-kanohi	face-to-face
Kāpō	to be blind
Kaupapa Māori	Māori agenda, Māori principles, Māori ideology – a philosophical doctrine, incorporating the knowledge, skills, attitudes, and values of Māori society
Koha	gift, offering
Kōrero	speak, speech, address
Kupu	word, vocabulary
Mana	spiritually sanctioned or endorsed influence, power, and authority
Manaakitanga	showing and receiving care, respect, kindness, and hospitality
Māori	Indigenous peoples of Aotearoa
Marae	courtyard – the open area in front of the wharenui, where formal greetings and discussions take place. Often also used to include the complex of buildings around the marae
Mārama	lucidity, transparency
Mātauranga	knowledge, wisdom
Maunga	mountain
Mokopuna	grandchild, grandchildren, descendant
Ngāti	prefix for a collective, tribal group
Pākeha	non-Māori; foreign
Pū	base
Pūrākau	ancient/historical narrative, story
Rākau	tree
Takatāpui	Māori who identify with diverse genders and sexualities including (but not limited to) lesbian, gay, bisexual, trans, intersex, queer
Tamariki	children

Tāngata whaikaha Māori	term used to describe Māori with lived experience of disability
Tāngata whenua	people born of the land – of the placenta and of the land where the people’s ancestors have lived and where their placenta are buried
Taonga	treasure, anything prized
Tautoko	support, verify
Te Ao Māori	the Māori world
Te Tiriti o Waitangi	the Māori version of the Treaty of Waitangi; forms the foundation of the contractual relationship between two internationally recognized sovereign nations – Māori, as tāngata whenua (people of the land), and the British Crown
Tikanga Māori	customary system of values and practices that have been developed over time and are deeply embedded in the social context
Tino rangatiratanga	absolute authority, sovereignty, self-determination
Tīpuna/Tūpuna	ancestors
Tūhono	to join, bond, attach, connect
Turi	to be deaf
Tūru	chair
Wahine/Wāhine	woman/women, female, feminine
Wairua	spiritual, spirit, soul
Waka	canoe, vehicle, conveyance
Wānanga	to meet, discuss, deliberate, consider, workshop
Whakawhanaungatanga	relationship building
Whai Ora	seeking wellness, consumer, service user
Whānau	to be born, extended family, family group
Whānau hauā	term used to describe Māori with lived experience of disability
Whāngai	to feed, nourish, bring up, foster, adopt, raise, nurture
Wharenui	meeting house

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Appendix – Ko Wai Au?/Who Am I? Positioning Ourselves in Connection to the Kaupapa

Helena *Ko Taupiri te maunga, ko Waikato te awa, ko Ngāti Mahuta te hapū, ko Tainui te iwi, ko Poihākena te marae, ko Helena Tuteao ahau.*

I was born in Wellington and moved to Auckland when I was 3, where I grew up in South Auckland and moved to Hamilton about 13 years ago, where I now live with my two beautiful children.

Kirsten *Ko Ōkahuātiu te maunga, Ko Waikākāriki te awa, Ko Takitimu te waka, Ko Te Whānau a Kai te iwi.*

On my dad's side our whakapapa is to various marae around Tūranganui-a-Kiwa. My paternal grandfather grew up in Waituhi, and my paternal grandmother grew up in Manutuke. They grew up in communities which were about 20 minutes out of Gisborne and so that wasn't too far for my grandparents to find love. My dad was whāngai (adopted) to his father's sister and raised by her. That was a blessing for us to have more whānau and have those relationships. Through my maternal whakapapa, I connect to Scotland. My grandparents came to Aotearoa during the 1950s, my grandmother from Aberdeen and my grandfather from Alloa.

I have two beautiful children. Ko Wairongo te mātāmua, Ko Raukura te Pōtiki. Through their paternal whakapapa, I have connections to Te Āti Awa, Ngāruahine, and Ngāti Porou. My whakapapa to this kaupapa is through my mum and her brother who are profoundly deaf; New Zealand Sign Language (NZSL) was our home language growing up, and through them I was socialized in the NZSL, including Ngāti Turi (Māori Deaf community). NZSL was an important part of our family, whānau; I like to make that known to people and acknowledge that.

Tristram *Ko Takitimu te Waka, Ko Ngaruroro te Awa, Ngāti Kahungunu ki Heretaunga Ngāti Porou oko Iwi, Ko Goddard raua ko Broughton oko whānau* tipuna. Ko Tristram Ingham ahau.

I was actually born in the United Kingdom (UK), but to a New Zealand father, and my mother is from the UK. I moved here at a very young age and grew up in Tāmaki Makaurau (Auckland), before moving to where I live now which is the capital Te Whanganui-a-Tara (Wellington) where I live with my lovely wife. I have three beautiful stepchildren and two amazing mokopuna who are under 2. My connection to this kaupapa is through a genetic neuromuscular condition inherited through my mother's side; so I, along with other members of my whānau, have lived experience with physical disability, since birth.

I studied medicine as an undergraduate, and I completed a medical degree at the University of Otago. I spent my first postgraduate years in clinical practice, as a hospital-based physician doing internal medicine. I was struck from a personal perspective that there was no academic teaching around disability in medicine; there was no visibility in the health and disability system, nor disability responsiveness in that system. There was very little opportunity for reasonable accommodation of disabled people to be heard either within our professions or in clinical services themselves. The whole concept was invisibilized.

From a professional perspective, given that Aotearoa New Zealand is a country that prides itself on being a relatively wealthy first world OECD nation giving a fair deal for all, I was surprised that significant inequities are faced by Māori and other ethnic minorities within the population. My decision to move into academic research was really to better understand the inequities that I saw existing for people with chronic health conditions and disability that led to acute presentations that could have been easily prevented with better primary healthcare and/or a holistic approach to care.

Huhana *My name is Huhana from the Waikato. Born and raised though in Taranaki under Te Maunga Taranaki. He's my wairua maunga. Whenever I need him he's there. I'm from Wereroa, Pukarewa, we're Ngāti Tahinga on the West Coast. We are Whakatohea.*

My nanny of about six generations ago married a Scotsman called John Alexander McGregor, and that's it. That's the only Pākehā. Then my great grandfather is Aboriginal. My grandfather was Navajo and my father is Sami. I have got two sons. My youngest is half Caribbean, and I have a Filipino grandson and two grandsons in total. So, a mixture of the earth from E Ngā Hau e Whā,[the four winds] from the four corners of the earth is my whānau.

I have MS (multiple sclerosis) which is progressive, and now I have lost all mobility. In the last few weeks [the doctors] don't know what's going on, is not easy. But that's life. It's the future and we've just got to embrace it and go with it. I've been involved in research for years, but I am struggling more and more with the written elements of things. It's really great to be able to participate in a kōrero and share stories and thoughts this way.

Bernadette *Ko wai au? ko Kurahaupō te waka, ko Ruapehu te maunga, ko Whangaehu te awa, ko Kauangaroa te marae, ko Ngā Wairiki, Ngāti Apa te iwi, ko Maraea Huatau, te tupuna.*

I was born and bred in Whanganui-a-Tara (Wellington). I'm a mother of three beautiful adult children, I'm delighted to be a nana with two mokopuna. I trained at Wellington Hospital then spent 20 years as a registered nurse in Sydney. I returned to New Zealand following a permanent work-related injury and had to change my career. I moved into research which I had resisted all my nursing career, because I liked the contact with people, and I thought I wouldn't get that in research. Strangely enough, I've been more motivated and feel like I can do far more as a researcher than I did as an intensive care nurse.

At the beginning of my research journey, I was one of only two Māori disabled researchers in my institution, and it was really challenging to learn and work in that situation. It's that "double jeopardy" impact of being both Māori and disabled that I really struggled within an unsupported academic environment. I wanted to work in a university that was Hauora Māori-based so I would have more support both culturally and academically. Part of my stubbornness working within a disabling institution and my understanding of both Te Ao Māori and the Pākehā world meant that the challenge was to stay there and challenge the "status quo." I wanted to bring other colleagues on-board and increase that understanding, because, if I didn't do it, who was I going to leave it to? If I wasn't willing to make the changes, I couldn't step back and expect someone else to do it. I was just lucky that I had the support of my husband, who without him it would have been a very lonely place to work.

I studied for a master's degree, and my experience was a very isolating, cultural experience, because the university didn't provide someone who had both Kaupapa Māori expertise and a knowledge of my disability research. My solution was to bring on whānau with that expertise, however, that was denied. Institutionally, it was seen as far too great a risk for a university to have whānau supporting a Māori researcher with lived experience of disability. He was allowed to do all the mahi (work) and provided me with the support I needed, but he couldn't get any formal acknowledgment. Whānau expertise was not valued, and without that support, I would not have completed my master's degree. This was institutional racism. We have challenged many of the "mainstream" academic approaches, and it's only in recent years that we have had the support of senior managers who have been addressing some of the institutional racism. That's been a very slow process, but it's slowly changing and it's good to see.

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Role of Culture and Legacy of Colonialism in Qualitative Research Methods with Persons with Disabilities in the Global South

26

Jorge Manhique and Action Amos

Contents

Abstract

In this chapter the authors reflect on the ability/possibility of qualitative research methods to enable persons with disability in the Global South to conceptualize disability and reflect on their lived experience. Disability studies theorists have recognized the importance of qualitative research methods in empowering persons with disabilities by lifting their voices. In this chapter we reflect on how research on disability in the Global South has been done. The chapter focuses on the case of persons with epilepsy and psychosocial disabilities (in Malawi) and

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persons with disabilities more generally (in Mozambique). Based on our own work as early-stage researchers, we reflect on our experience of engaging persons with disabilities as informants. The chapter highlights the role of culture and the legacy of colonialism as issues that researchers must deal with to ensure that disability studies in the Global South is at the service of those with disabilities and cease from engaging in predatory practices.

Introduction

Qualitative research methods have been considered important in lifting the voices of communities traditionally marginalized by mainstream society. As feminist and Black studies, disability studies have embraced qualitative research in part for its potential to enable those with disabilities to speak up and challenge the hegemony and control that experts and medical professional had, for so long, over their bodies, minds, and lives.[1] Guided by the rights paradigm, disability studies using qualitative methods have the potential to challenge power relations (Stone & Priestley, 1996). Despite this potential, disability studies have not lived up to its promise for the 80% of persons with disabilities from the Global South (Goodley, 2015). Disability studies theory and models used to examine disability issues in the Global South have been described as inadequate (Meekosha, 2011) and as representing a “new form of colonialism” (Bezzina, 2019; Grech, 2009; Meekosha, 2011). This chapter discusses the ability/possibility of qualitative research methods to enable persons with disabilities in the Global South to conceptualize disability and reflect on their lived experiences.

The first part of this chapter briefly reviews the models that have informed research on disability, and how these theories have influenced the understanding of disability, mental health, and epilepsy in the Global South. The chapter proceeds to reflect on empirical research on disability in the Global South. Critically, the authors observe that research on disability in the Global South has, at the best, been extractive and contemptuous. The third part examines the role of culture and more specifically language when applying qualitative research methods. It calls for greater consideration of the role that language and the legacy of colonialism play when conducting research with persons with disabilities in the Global South, to ensure that epistemic violations are not perpetuated and effectively reframe the Global South spaces as spaces of agency, that is, where vernacular ideas and knowledge of people with disabilities prevail and is equally valued. The chapter draws on reflections from ongoing research projects that the authors are separately involved in as early-stage researchers in Malawi and Mozambique and the review of relevant literature.

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[1] This is not to say that quantitative research methodologies are unable to address issues of power. It is more to emphasize the ability of qualitative research methodologies to enable participants to analyze and communicate their perspective on the material conditions they are in.

Despite the controversies that surround the term, the authors of this chapter use the term "Global South" consciously to refer to countries that have in common past experiences of living under colonial domination (Grech, 2015).

Review of Models/Theories of Disability

This section focuses on some of the most significant – in terms of policy influence – approaches to/models of disability, namely the individual model (also known as medical model), the social model, the normalization model, and the human rights model.

Briefly, the medical model refers to an approach which regards disability as essentially an individual problem, "steaming from functional limitation or psycho-social losses" (Oliver, 1996, p. 32). The medical model treats persons with disabilities as objects that need to be fixed to fit within the societal structure designed for "able" bodies and minds – usually white middle-class men. As such, medicalization became the dominant form through which disability issues are addressed. Rehabilitation and vocational programs are conceived to fix the person to be able to function in society without recognizing societal values, attitudes as well as the environment that are discriminatory and inaccessible. Two implications result from the application of the medical model to policy design and implementation, namely that "(i) disabled persons need to have shelter and welfare and (ii) impairment can foreclose legal capacity" (Degener, 2016). This approach to disability is founded on the notion that people with impairments are incapable of meeting social expectations such as working, acquiring an education, or determining where and with whom to live, among other things (Aguilar, 2017).

In contrast, the social model of disability focuses on "society rather than on the individual" (Degener, 2016). Although there are multiply versions of the social model (Lang, 2001; Shakespeare, 2006), scholars generally agree that the dominant kind has been the one developed by the Union of the Physically Impaired Against Segregation (UPIAS), documented in the Fundamental Principles of Disability published in 1975, and subsequently developed by Mike Oliver (1990), Finklestein (1980), and other prominent scholars, predominantly white male with physical disability (Shakespeare, 2006). Nevertheless, "common to all variants of the social model is the belief that, at the root, 'disability' and 'disablement' are socio-political constructions" (Lang, 2001, p. 2). The social model makes a clear distinction between disability and impairment (Shakespeare, 2006, p. 13). Impairment refers to "a condition of the body or the mind," and disability refers to "a situation, caused by social conditions, which requires for its elimination" (UPIAS, 1975, p. 3). In addition, the social model rejects the predominance of experts in the lives of disabled people, instead arguing for independence and full control of their own lives (Oliver, 1996). Thus, by emphasizing the manner in which disability is socially produced and issues of power – over disabled people – "the social model gives precedence to the importance of politics, empowerment, citizenship and choice" (Lang, 2001, p. 4).

Critical disability study theorists have disputed many implicit and explicit assumptions that underpin the social model of disability. Those include the fact that the social model concepts and theory are not appropriate to understand the lived experience of persons with disability in the Global South (Meekosha and Shuttleworth, 2009; Grech, 2015). Meekosha (2011), for example, proposes that the phrase "social suffering" be used instead. The social model's limitations have also been highlighted by critical disability theorists, such as the dichotomy of impairment and disability, the "downplay of pain and suffering" (Hall, 2019; Shakespeare, 2006; Meekosha, 2011), and the excessive focus on disability identity, excluding other identities from the analysis of persons with disabilities' lived experiences (Goodley, 2017). Further, critical disability theorists critique the exclusion of the voices of the large proportion of persons with disabilities (80%) who live in the Global South (Goodley, 2017).

The normalization principle emerged from Scandinavia, in particular from Sweden and Denmark (Perrin, 1999). Scholars trace its origins to the development of the modern social welfare societies, especially in Sweden in the late 1930s and 1940s, with its emphasis on principles of equality and the right of all human being to be guaranteed a good standard of living. In particular, the normalization principle places specific obligation on the "state to provide social services, if necessary," to guarantee good standard of living (Perrin, 1999, p. 181). Primarily applied in relation to persons with psychosocial and intellectual disability, the normalization principle was later expanded to include other groups of persons with disabilities. Accordingly, normalization means making available to all persons with disabilities, "patterns[2] of life and conditions of everyday living which are as close as possible to or indeed *the same as* the regular" (Perrin, 1999).

In the disability rights field, the human rights model is often referred to be in opposition to the medical or charity approach to disability and sometimes confused with the social model of disability (both described above). An important moment for the affirmation of the human rights model of disability was the adoption of the Convention on the Rights of Persons with Disabilities (CRPD) by the United Nation General Assembly in 2006. The significance of the CRPD lays in the fact that it introduces a paradigm shift in the way disability and persons with disabilities are considered (Degener, 2016). Paradigm shifts matter because they "mark the moment when traditional frameworks became ineffective, and when existing social theories no longer sufficiently explain social realities" (Collins, 2019). The CRPD considers persons with disabilities as subjects of rights and capable of exercising their rights. The CRPD embraces the concept of equality of opportunity by recognizing the need to create an enabling environment by adopting the principles of universal design, a

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[2] Normal patterns of conditions of life can be viewed in terms of eight different elements: 1. A normal rhythm of the day. 2. A normal rhythm of the week. 3. A normal rhythm of the year. 4. The normal experiences of the life cycle. 5. Normal respect for the individual and the right to self-determination. 6. The normal sexual patterns of one's culture. 7. The normal economic patterns and rights of one's society. 8. The normal environmental patterns and standards in one's community (Perrin, 1999, citing Nirje, 1993).

set of supports, and reasonable accommodation when needed to ensure that all persons with disabilities can participate fully in social, cultural, political, and economic life, on equal basis with others. Different from the previous models discussed in this chapter, the human rights model "values impairment as part of the human diversity" while acknowledging other identities (Degener, 2016), in clear recognition of the heterogeneity of disability and intersectionality.

In the field of disability and development, the human rights model has helped to inform what is known as the Human Rights-Based Approach (HRBA) to disability and development. Broadly understood, the human rights-based approach to development is a process where development and human rights merge and become "conceptually and operationally inseparable parts of the same processes of social change" (Uvin, 2004. p. 175). According to Uvin (2004), there are two implications that result from the adoption of the HRBA to development. The first is that the "goal" of development work changes, as it focuses on claims and not charity. By shifting the focus to claims, the development process is "deeply political" and not technical or legal. In this sense, a HRBA to development is not about "asserting the existence of legal claims" [. . .], "but about political struggles, in which human rights are tools that crystalize the moral imagination and provide power in the political struggle" (Uvin, 2004, pp. 176). Secondly, HRBA also changes the way development programs are implemented (the process). In this sense, development agencies must look inward too and conform their processes with human rights standards.

Critiques of the human rights model often suggest that human rights norms are mainly Western-centered, hence more effective in Europe and the United States than elsewhere in the world (Katsui, 2008; Uvin, 2004). The CRPD is the case in point. While the negotiation process has been hailed as participatory, driven by the organizations of persons with disabilities including a significant presence of African organizations of persons with disabilities (Viljoen & Biegon, 2014), it is important to consider the knowledge production context in which the CRPD was negotiated. In Europe, the USA and Canada, the field of disability studies emerged in the 1970s – 50 years ago (36 years before the time of adoption of the CRPD by the UN General Assembly in 2006). The social model of disability was established in 1970/80 (UPIAS, 1976), and in Scandinavia the normalization principle emerged in the 1960. The USA had its own American with Disabilities Act (ADA, 1990). This gave OPDs from the West a knowledge backing for the CRPD negotiation process, and the outcome document, it can be argued, still reflects the dominant Western view of human rights, which is based on a strong recognition of individual rights, individual autonomy, and the perspective of various models developed in the West: the social model of disability, the normalization principle, and key concepts such as reasonable accommodation.

Linked to the previous point, critics also question the idea of "universality" embedded in the human rights model and how it is operationalized in practice. They argue that the idea of human that underpins the human rights discourse is largely inspired by European ideas of humanity (Mutua, 2001). Human rights are conceptualized on the basis of a European image although with universalistic ambitions (Mbembe, 2017). Because of that, "new voices are raising to proclaim that [*the idea of]* universal human either does not exist or is limited to what is common, not to all men [*and women*], but only to some of them" (Mbembe, 2017, p. 28). In the field of disability, scholars have denounced that while the CRPD may be benefiting mainstream persons with disabilities, indigenous persons with disabilities are still being excluded, due to the failure of the drafters to recognize and consider the intersection between disability and indigeneity (Hickey, 2020).

The CRPD Committee has recommended, under article 32 of the CRPD, all African countries[3] reviewed after 2018 to consider ratifying the Protocol to the African Charter on Human and Peoples Rights on the Rights of Persons with Disabilities in Africa (hereinafter, African Disability Protocol) adopted by the African Union in 2018. While the CRPD Committee does not articulate how and why the African Disability Protocol relates to article 32, it can be argued that it gives further guidance to State parties on how to mainstream the rights of persons with disabilities in development cooperation programs in the African context. By recommending the ratification of the African Disability Protocol, the Committee seems to be recognizing the importance of contextualizing human rights, in this case the rights of persons with disabilities. For instance, while both the CRPD and the African Disability Protocol contain the right to an Adequate Standard of Living (CRPD Article 28 and African Disability Protocol Article 20), which are similar in substance, the right to access justice, which is key to ensure that the right to an adequate standard of living is claimed and enforced, differs significantly in both instruments (CRPD Article 13; African Disability Protocol 13). The right to access justice contained in the African Disability Protocol makes references to customary law, which is a distinctive feature of African justice systems. The African Disability Protocol also contains rights that are not explicitly expressed in the CRPD, such as the right to self-representation, the rights of youth and older people with disabilities, among others. These issues reflect the unique African context, namely the fact that Africa has the youngest population in the world – 20% aged 15–24 (UN Economic Commission for Africa, 2017), but also increasingly an aging population, which is expected to increase threefold – from 58.7 in 2017 to 225.8 in 2050 (UN Economic and Social Affair, 2017, p. 5), and their exposure to neglect and violence.

What the above review suggests is the limitation of traditional disability models (generated in the Global North) to account for disability experiences everywhere, despite claims of universality (Perrin, 1999, p.182). The application of these models is essentially top down, paying little attention to local contexts (Katsui, 2008). In this sense, their application is a new form of colonialism (Bezzina, 2019). Critics call for "grounded realism," one which gives priority to "socio-cultural, political, historical and economic nuances of different contexts" (Grech, 2009). This poses an epistemological challenge, one that puts northern theories, models, including the "universal" standards of human rights, in dialogue with local ways of staying and being, history and the whole contextual environment (Ife & Tascón, 2016; Stone, 1999).

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[3] See the Concluding Observation of Rwanda, Senegal, and Niger.

Conceptualizations of Mental Health

As disability, the conceptualizations of mental health have been derived from various perspectives across history and continue to evolve (Misra et al., 2019). There are conceptualizations that focus on sociological or sociocultural factors while others focus on medical or biological aspects (Aneshensel et al., 2013; Seeker, 1998). Some emphasize the absence of psychopathological symptoms and others link mental health to constructs such as well-being, happiness, and self-realization (Jeste et al., 2015; VanderWeele et al., 2019). Fernando (2012) suggested that the Western notions of normal behavior, health, and psychopathology are quite different to conceptualizations of mental health of communities in the Global South. Three examples that come out clearly from you research illustrate this distinction.

The first is cultural and spiritual. Many participants stated that mental health is dictated by the causes of "illness," the most prevalent of which are witchcraft or demonic possession, both of which require spiritual cleansing. Mental health was portrayed as "retribution (punishment) from the creator," "a curse that comes your way by coincidence," and "generational ill actions (payment for evils done by forefathers)" in the response. Molelekoa (2020) confirms that in Africa, mental health is understood in terms of its causative form, which is supernatural in nature and requires spiritual intervention from God or ancestors.

The second is behavioral. Some individuals recognized behavior as a crucial symptom of mental instability. Participants highlighted things like "aggressiveness," "senseless speaking," "eating from bins," and "not meeting an acceptable degree of normalcy." It was widely assumed that if a person did display inappropriate behavior, they would be labeled as mentally ill. As such, one of the most crucial signs of mental illness, according to some participants, is one's behavior. The causes of behavioral symptoms in the Global South are generally linked to bewitching and demonism, just as they are in cultural and spiritual understandings of mental health.

The third is medical. Participants also characterized "sound" mental health as the absence of psychopathology, favoring medical-model-biased approaches as defined earlier in this discussion. Rapp (2007) argued against the medical model method, claiming that it encourages the impacted to be passive by considering him or her as a patient or client with no further participation to the study process. Patients' views are frequently ignored in the Global South due to a perceived lack of competence to speak up (Amos, 2021).

According to the World Health Organization, mental health is "a state of well-being whereby individuals recognise their abilities, are able to cope with the normal stresses of life, work productively and fruitfully, and make a contribution to their communities" (WHO, 2003, p. 7), and yet, understanding sociocultural variation in operationalizing this concept remains of profound importance – this can influence the way in which mental health challenges are best addressed in a population (Seeker, 1998).

To design effective policies or interventions to improve mental health, it is necessary to know and understand the conceptualizations and perspectives held by the community of interest to successfully address mental illness and well-being in the specific cultural context (Huppert, 2009). This is especially relevant in lower-middle income countries (LMIC) that receive support from developed countries to design and implement mental health policies (Cox & Webb, 2015). Similarly, when undertaking qualitative research, one of the main challenges is to balance or adopt a contextualized definition, coherent with the understanding of the people affected.

Several studies, as in many other Sub-Saharan African nations, have underlined the importance of taking cultural factors into account when undertaking mental health research or programs (Woods-Jaeger et al., 2017; Yoder et al., 2016). For example, in Malawi, there exists overlap between spiritual, biomedical, and psychosocial explanations for mental health problems (Samuels, Jones, & Bassam, 2017; Skylstad et al., 2019). This has not been a key consideration when implementing mental health programs in Malawi. This explains the stigma associated with mental health in this cultural context. Stigma decreases the likelihood of patients living in Malawi to be included in all aspects of life. Many in Malawi, due to their understanding of mental health, instead of getting medical services support prefer the consultation of traditional healers and religious leaders (Yoder et al., 2016). However, mental health policies – which largely endorse a medical approach – do not incorporate these different mental health perspectives and do not engage with the different agents validated by the community as mental health promoters, such as religious or traditional healers (Akol, Moland, Babirye, & Engebretsen, 2018; Skylstad et al., 2019; Yoder et al., 2016). In fact, Corbin and Miller (2009) suggest the biggest challenge in this area is integrating Western concepts of psychosocial healing with non-Western concepts. Such an approach must be based on research that genuinely engages with the voices of persons with psychosocial disabilities in the Global South and vernacular ideas and conceptualizations of mental health and disabilities, in ways that traditional disability theories and models have not. This points to the role of language in qualitative research methods in the field of disability in the Global South, and the legacy of colonialism, all discussed below.

Disability Studies Models and Research Methods

Since its onset, disability studies have been suspicious of traditional research methods and tenants in social science research, much like feminist and Black studies (Rioux, 1994). Disability scholars have denounced the predatory and exploitative nature of theories and paradigms informing earlier research on disability (Stone & Priestley, 1996). In the name of objectivity and operating under positivist understanding of knowledge, research on disability served to advance researchers – mainly non-disabled – academic carrier with little impact on the material condition of the lives of persons with disabilities (Stone & Priestley, 1996).

However, this is not specific to disability studies. The roots can be traced to modern epistemology underpinned by enlightenment tenants, which has been denounced by both decolonial and post-development scholars (see Esteva, 2010; Santos, 2018). The “commitment to rationalism” – the belief in human reason which accord them superiority over nature and other animals; the “belief in fundamental dualisms, such as reason versus emotion, mind versus body, culture versus nature, absolutism versus relativism, and objectivity versus subjectivity; the assumption that there is an ontological divide between humans and nonhuman animals and nature; and universalizability as a criterion for assessing the truth of ethical and epistemological principles" (Warren 2015, cited by Santos, 2018, p. 304) have all contributed to the hegemony of Western knowledge with the support of Western military superiority and economic power. Critically, the "hegemonization" of Western knowledge occurred at the detriment of other – non-Western knowledge – bringing about "epistemicide" – described as the "destruction of an immense variety of ways of knowing that prevail mainly on the other side of the abyssal line – in the colonial societies and sociabilities" (Santos, 2018, p. 8). Therefore, "the economic and political injustices that characterize the world order today result in, and are sustained by, the cognitive injustice that exists at the core of the production of knowledge since the beginnings of the modern colonization of the world" (Barreto, 2014, p. 397).

We similarly argue that qualitative research on disability in the Global South has been used in extractive and contemptuous ways. It is extractive in the sense that it concentrates on what fits within Western paradigms and ideas of disability. Contemptuous in the sense that it dismisses what does not fit into those models as irrelevant, frequently classified as "traditional beliefs, harmful habits, and preconceptions," and, hence lacking epistemic importance. For instance, in Amos study on epilepsy in Malawi, participants highlighted a list of foods that are advised by the witchdoctor as to be avoided as key contributing elements to increased seizures. However, because of the lack of understanding of this reality by traditional researchers, this is commonly rejected and considered as a myth. Some participants indicated that avoiding these foods has helped them to have stability in their condition. In fact, in our experience, the design of leading questions in qualitative research, such as "Tell us the most widespread beliefs/myths regarding epilepsy/mental health," already directs respondents to discuss something they may not believe is a myth to satisfy the researchers preconceived assumptions. Understanding the meaning of mental health in the context of the research is critical since the people who are affected respect their traditional or cultural understanding and their lives and well-being is informed by their tradition and culture.

As observed by Shakespeare (2006) in relation to social model theorist "because most non-British disability research has not been based on the impairment/disability distinction and has not adopted the strong social model version of the social-contextual approach, it has conveniently been ignored or rejected as inadequate or mistaken" (Shakespeare, 2006, p. 10). Additionally, the concept of Disability Inclusive Development (DID), that has recently animated INGOs and donors, is disconnected from local narratives of what development, participation, and other related concepts mean for those with disabilities (Rodríguez, 2021).

We further argue that careful consideration of the ways that disability is understood and lived in the Global South is of paramount importance, not only to develop a local robust understanding of what it means to be a person with disability in these spaces, but also to ascertain a position of strength which would enable a fair dialogue with more established theories and ways of understanding disability in other parts of the world. By doing so, research on disability will contribute to "reframe the Southern space(s) and subject as one of agency" (Grech, 2015, p. 13). But, to do this, researchers need to confront the legacy of colonialism which continue to shape the condition (of exclusion and marginalization) under which persons with disabilities live today in the Global South (Grech, 2015). In the section that follows, we reflect upon the element of language as a particular legacy of colonialism and what it means for qualitative research methods.

Language in Qualitative Research

Qualitative researchers adopt an epistemological position described as interpretivist in the sense that it "stresses the need to understand the social world through an examination of the interpretation of that world by its participants" (Bryman, 2012), and an ontological position described as constructivist which implies that social properties are outcomes of the interaction between individuals, rather than phenomena "out there," separate from those involved in its construction (Bryman, 2012). It proceeds from this that language is an important tool to describe the social world.

The quest to understand disability in the Global South must take into consideration the legacy of colonialism (Grech, 2015). Language represents a significant part of that legacy in the sense that qualitative research on disability in the Global South has been done with recourse to colonial languages, on the one hand, as tool to gather data and, on another hand, to "describe" the experience of disabled subjects in journal articles.

As early-stage researchers currently conducting research with persons with disabilities, we have been experiencing first-hand the impact of colonial legacy. As part of the fulfillment of his PhD program, Manhique is in the early stage of conducting research on the inclusion and participation of persons with disabilities in development programs. The objective of the research is to identify and explain the factors that determine the inclusion and participation of some groups of persons with disabilities and the exclusion of others, from the design and implementation of international cooperation development programs. Specifically, his research focusses on European Union funded projects in the domain of gender-based violence and social protection in Mozambique. Semi-structured interviews and focus group discussions are being used to gather stakeholders' perceptions about inclusion and participation of persons with disabilities.

As part of a Master program, Amos undertook a review of best practice research on epilepsy (Amos, 2020) and evaluated the ethical practice of NGOs in mental health research (Amos, 2021) using participatory methods. In his review, it became evident that medical and western approaches and concepts dominated research in mental health, ignoring local or cultural context in all aspects such as language and what was to be accepted as the norm or myths.

In the first research (Manhique's study), informants were asked to reflect on two key concepts used in the study, namely: development and participation; and were encouraged to use words/expression in local languages that could best describe those concepts. The responses and reactions of the informants reveal in one hand the struggle, particularly among youth with disabilities, to communicate and/or express in local language. On another hand, it reveals how, for utilitarian reasons – namely the need to fit the world designed by others (colonial masters) – encourage those with disabilities to switch from using and expressing in local languages to using colonial languages. As noted by one of the informants:

> "I used to speak changana[4] when I was a child, but when I lost my hearing capability, I gradually lost the ability to communicate in changana as I needed to learn sign language and in school they only teach in Portuguese"... "if you don't know how to speak Portuguese, you will have problems to learn... Learn Portuguese was important to remove the barrier to education."

On another hand, research reports published in journal articles are written in colonial languages making them inaccessible to the audience they are supposed to serve and support – persons with disabilities.

In recognition of this legacy, in our research we deployed different strategies. First, the research project was presented to OPD leaders in the language that they are more comfortable with. They had opportunity to comment and propose changes to the research project – for instance in one of the consultation meetings, it was suggested to include the concept of disability among key concepts to be discussed/defined. Second, when selecting research informants, we were cognizant of the heterogeneity of the disability movement and the fact that within the movement there are groups that are more marginalized than others (WFD, 2019). Previous research has mainly enabled established groups – usually urban men with physical disabilities – to participate (Bezzina, 2019; Goodley et al., 2019). Those are usually war veterans that became disabled fighting in the colonial war.

Third, to engage potential informants, it was important to create the conditions that enable each of them to participate. This means addressing barriers created by their (lack of) material conditions. As such, support for transport, meals during the focus group/interviews or workshops, and small fees to ensure they have something to give their family that day when they return home. In defining the amount, we made sure that "participants are not unduly induced to participate" (Grischow et al., 2021, p. 171) and that the amount was appropriate for that context (urban, rural, cost of living). These arrangements enabled people such as Maida,[5] a woman with physical disabilities from the Mandimba district in Niassa Province, to participate. Maida is the leader of local OPDs involved in sports for persons with disabilities. She is aware of how important it is for women with disabilities like her to participate in community meetings and activism. However,

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[4] Local language of Southern Mozambique.

[5] A pseudonym.

Maida, who is a single mother of three, faces economic difficulties in participating. She has been a beneficiary of the basic social security benefit ($8/month) since 2012. With this amount, and small savings, she managed to open a small stall at the local market where she sells tomatoes. Participating in community meetings often means difficult decisions, between going to the market to sell and ensuring livelihood for herself and her children and/or participating in such meetings. As she explains:

> "If I had a husband, we could split up: I would go to the market, and he would go to the field (to grow corn). But this way, I must divide myself between the farm and the business so that I can survive with the children and send them to school. So, I would like God to help me to become a civil servant."

She further explains:

> ". . . there are meetings that I usually go counting on the meeting's subsidy. . . But there are other meetings where you just have lunch, go home and regret: 'Oh, if only I'd gone to the market'. But you have to learn, it's not just money."

In turn, in Amos epilepsy and mental health research, two tactics have been used to ensure that culture is ethically recognized and that imposed conceptualizations are avoided.

First, study participants are engaged as active research assistants or researchers, which replaces the affected participants' passiveness. The author is such an example as he is a person with epilepsy. Second, research participants' opinion is valued. Their notion of mental health or epilepsy, for example, which was rarely examined in traditional research, was considered in the study. This solves the problem of imposing a foreign approach to research informants (Amos, 2020). Finally, researcher reflexivity was important in dealing with the often considered researcher's prejudice immunity. Many researchers are unable to accept responsibility for their personal opinions, which can sway the outcome of a study. Previous research reveals that understanding, detecting, and counteracting the influence of stigma between researchers and participants necessitates knowledge of one's own preconceptions or prejudices (Goodman et al., 2017).

While we acknowledge the competing researchers' interests – academic promotion, activism, social justice, and so on – researchers engaging in disability studies in the Global South must be cognizant of their "ethical responsibility to research alongside disabled persons, to research with disabled persons, and not to engage in predatory research practices that advantage the research without reciprocation" (Castrodale, 2017, p. 46). Furthermore, discussion about the legacy of colonialism in the practice of disability studies in the Global South must occupy center stage to ensure that epistemic "violations and subjugations are not maintained" (Grech, 2015). Only then, qualitative research methods in the practice of disability studies can be put at the service of persons with disabilities and cease to engage in oppressive and predatory practices (Stone & Priestley, 1996).

Conclusion

While promising, the use of qualitative research methods in research on disability in the Global South has not contributed to the emancipatory promise of disability studies. This is because researchers applying traditional disability theories, briefly presented above, have not engaged critically with local cultures, and have not taken into consideration the legacy of colonialism when conducting research on disability in the Global South. We argue that researchers conducting research on disability in the Global South using qualitative research methods must be cognizant of the role of language and the legacy of colonialism in perpetuating epistemic violence and subjugation and adopt strategies that promote greater involvement and participation of persons with disabilities in research. Drawing from our ongoing research, we highlighted strategies applied that can contribute to this goal. These include: engaging persons with disabilities as active research assistants or researchers and equally valuing their opinion; grounding research in local language and encouraging research participants to reflect on their local language rather than using colonial language; being cognizant of power inequality in society including within the disability community and provide support to ensure marginalized persons with disabilities can meaningfully participate; and finally, developing researcher reflexivity to ensure researcher's own preconceptions do not sway the research outcomes.

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Inclusive Research: Doing Participatory and Emancipatory Research with People with Intellectual Disabilities

Anne-Marie Callus

Contents

Abstract

This chapter discusses the origins, principles and practices of doing inclusive research with persons with intellectual disability as co-researchers. The relationship between inclusive research on the one hand and participatory and emancipatory research on the other is considered together with the link to self-advocacy. The chapter also provides examples of inclusive research and discusses the methods that are mostly used in inclusive research. The role of academic researchers and co-researchers with intellectual disability is also discussed, both in conducting research and in writing about the research carried out.

Keywords

Inclusive research · Self-advocacy · Intellectual disability

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Introduction

Although the slogan "nothing about us without us" did not originate with the disabled people's movement, it has been used by disabled activists to such an extent that it has become practically synonymous with this movement (Charlton, 1998). Its premise – that nothing about disabled people should be done without their direct involvement – holds for the development of legislation and policies, for service provision, and also for conducting research. It also holds for all disabled people, including persons with intellectual disabilities (referred to as persons with learning difficulties/disabilities by British authors).

It is through inclusive research that persons with intellectual disabilities are directly involved in carrying out research. Inclusive research borrows from the principles and practices of emancipatory disability research, participatory research, and self-advocacy to create a unique approach to doing research. This chapter first traces the origins of inclusive research and then discusses some examples of inclusive research projects. It then considers the conceptual framework of inclusive research and the research methods that are typically used. Following this, the chapter discusses issues related to the provision of support for persons with intellectual disability to engage in research and how inclusive research is written about, before concluding by drawing together the main issues discussed.

The Origins of Inclusive Research

The term "inclusive research" was coined by Jan Walmsley in an article published early this century on "a range of research approaches that have traditionally been termed "participatory" or "emancipatory," broadly speaking research in which people with learning difficulties are involved as more than just research subjects or respondents" (Walmsley, 2001, pp. 187–188). Walmsley identifies normalization (later known as social role valorization) (Wolfensberger & Tullman, 1989 cited in Walmsley, 2001) and the social model of disability (Oliver, 1983) as two main influences on the emergence of inclusive research. The ideas underpinning the theory and practice of normalization and the social model have also contributed, albeit in different ways, to substantial improvements for people with intellectual disability in many countries to enjoy their rights and experience a better quality of life.

One of the most significant developments has been the realization of the perspectives of persons with intellectual disability. "Realisation" is here being used in two senses: in the sense of people working and living with people with intellectual disability realizing that the latter's perspectives were valid and that it was important to take them into account in their work; and in the sense of taking steps to make the articulation of these perspectives a reality. In research, the first step entailed involving persons with intellectual disability as research participants. In itself, this was a significant step given the long history of doing research about persons with intellectual disability without their perspectives being taken into account (Walmsley &

Johnson, 2003). One wonders if these persons even knew that they were the subject of research. Works which presented their perspectives – one of the earliest being Bogdan and Taylor (1982) – were therefore a very important development.

The second step built on this development through research projects including persons with intellectual disability in *all* stages of the research process and therefore also as researchers. Apart from the influences mentioned above, another influence on inclusive research was self-advocacy (Walmsley, 2001; Walmsley & Johnson, 2003). As Sutcliffe and Simons (1993) report, self-advocacy means speaking up for yourself and others, making choices and acting on them, speaking with people and holding meetings, and making things happen. All of these aspects of self-advocacy are compatible with conducting research, and inclusive research can be seen as a specific way of doing self-advocacy. In fact, Bigby, Frawley and Ramcharan (2014) link the development of self-advocacy in Australia with the development of inclusive research.

A very important aspect of self-advocacy is that persons with intellectual disability are provided with support from others, usually nondisabled persons. The parallel in inclusive research is that of professional (often academic) researchers providing support to coresearchers with intellectual disability. Discussions about inclusive research also refer to participatory research and emancipatory disability research as having had significant effects on the development of inclusive research (see Walmsley, 2001; Walmsley & Johnson, 2003; Nind, 2014). In line with participatory research, inclusive research involves those who are usually the subject of research as researchers in their own right. In fact, in North America it is referred to as a form of participatory action research (see McCulloch, 2011; Ward & Trigler, 2001). The links between the two are further reinforced by references to Paulo Freire's work by many of those writing about inclusive research, including Walmsley (2001), Stevenson (2014), Nind (2017), and Embregts et al. (2018). This article uses the term "inclusive research" since it refers to the specific way in which persons with intellectual disability are involved as coresearchers.

One particular characteristic of inclusive research is that it also builds on the principles of emancipatory disability research. In fact, in line with these principles – as set out by Barnes (2002) – in inclusive research, researchers hold themselves accountable to persons with intellectual disability, use a social model understanding of the nature of intellectual disability (and therefore focus on socially constructed barriers), address such barriers in research by using methods that are accessible, privilege the perspectives of persons with intellectual disability and their experiences, and use research as a tool for improving the lives of persons with intellectual disability. As Barnes (1992) writes elsewhere, "researchers must put their knowledge and skills at the disposal of disabled people. They do not have to have impairments themselves to do this" (p. 122). Inclusive research is an excellent example of how this can happen.

In her first article on inclusive research, Walmsley (2001) notes that inclusive research was at risk of being marginalized. Fourteen years later, she describes being "amazed to see it blossom into an international phenomenon" (Walmsley, 2015, unpaged). In fact, since the first projects carried out in the 1990s, inclusive research has become a well-established approach to doing research. Some examples of inclusive research projects are discussed in the next section.

Inclusive Research Projects

In her 2001 article, Walmsley felt the need to create a new term to reflect the uniqueness of this research approach when compared to other ways of doing research, including participatory and emancipatory disability research. It is, however, not unique in the sense of comprising one way of doing research which is replicated by all those doing inclusive research.

Some of the first research projects that adopted inclusive approaches focused on telling the life stories of persons with intellectual disability. One example *Women with Intellectual Disabilities: Finding a place in the world* which, as the editors say, "is written by, with and about women with intellectual disabilities" from Australia, the Czech Republic, England, Iceland, New Zealand, Norway, Slovakia, and the USA (Traustadóttir & Johnson, 2000, p. 9). Other examples of this type of inclusive research are the accounts of the lives of persons with intellectual disability in Flanders, Belgium, compiled by the self-advocacy organization Onze Nieuwe Toekomst (referred to by Roets et al., 2005), and the personal stories in some of the chapters in Mitchell et al.'s (2006) *Exploring Experiences of Advocacy by People with Learning Disabilities: Testimonies of Resistance*. The majority of the authors with intellectual disability who contributed to this volume are members of self-advocacy groups, mostly but not all in the UK – an attestation of the close links between self-advocacy and inclusive research at least in the early stages.

These and similar publications build on what was achieved by work such as that by Bogdan and Taylor in their presentation of the life stories of Ed Murphy and Pattie Burt, which they reconstructed from hours of recorded open-ended interviews. As mentioned above, Bogdan and Taylor's (1982) book was groundbreaking in presenting the lives of two persons with intellectual disability from their own perspective. What the contributors to books such as the ones by Traustadóttir and Johnson (2000) and Mitchell et al. (2006) did was to support persons with intellectual disability to write their own life stories and have them published in their names with the nondisabled people who provided support listed as coauthors. The result is that "[t]hey present to the reader an active and assertive group of people that counters the passive image of people with learning disabilities that is so often portrayed" (Mitchell, 2006, p. 7). Furthermore, by presenting the perspectives of persons with intellectual disability in pieces written (or cowritten) by the persons themselves, these and similar publications also show how they are capable of reflecting on their lives and articulating their perspectives.

Another development was for persons with intellectual disability to conduct research about the lives of other persons with intellectual disability. One of the first such studies, reported on by Sample (1996), was conducted in the USA and focused on the recreational and leisure needs of adults with developmental disabilities. Very often, such research is conducted by self-advocacy groups in partnership with academic researchers, a clear indication of the similarities of inclusive research to participatory and emancipatory disability research. One study, conducted in the 1990s by the Bristol Self-Advocacy Group, was aimed at finding out about how other self-advocacy groups work (Williams, 1999). Self-advocacy has continued to be linked closely with inclusive research. McCulloch's PhD thesis is built on the use of participatory action research with four Canadian persons with intellectual and developmental disabilities "to practise being self-advocates" (McCulloch, 2011, p. i). More recently, Central England People First carried out inclusive research about the group's own history (Walmsley & The Central England People First History Project Team, 2014).

Inclusive research has also been conducted in various countries about different subjects that are of interest for persons with intellectual disability. Taylor et al. (2007) present the results of research carried out with service-users with intellectual disability in the UK. Frankena et al. (2019) synthesize the results of inclusive health research projects carried out in Ireland, Northern Ireland, and The Netherlands. Vega-Córdova et al. (2020) report on an inclusive research project on "the cognitive accessibility of public spaces and services in a Chilean city" (p. 318). Other research subjects include independent living in a study carried out in Catalonia, Spain (Coll et al., 2016), and overprotection in a study carried out in Malta, a study that I carried out with a coresearcher with intellectual disability (Callus et al., 2019). For these studies, ad hoc research teams were created. There are also research teams whose members remain more or less the same from one project to the next. These include the Building Bridges Research Group in the UK which is part of a nongovernmental organization (Building Bridges Training, 2020) and two inclusive research networks based at a university, one in Ireland (Trinity College Dublin, 2020) and one in Australia (Centre for Disability Studies, 2021).

The publications cited in this section provide some examples of the type of inclusive research projects that have been carried out in various countries. While they attest to the variety of topics researched, research team set-ups, and methods used – as seen also later in this chapter – one of the characteristics that they share is that, while the projects are situated in different continents, the countries mentioned are almost all placed in the Global North. There are examples of participatory research in the Global South, such as the video project with disabled people in Burkina Faso by Bezzina (2019). Any developments in the area of inclusive research itself would need to grow organically within the context of different countries. They would also need to take into account the issues faced by disability researchers in the Global South, especially the risk that researchers from the Global North carry out this research from their own epistemological standpoints and without regard of the socioeconomic and cultural context in which the research is being carried out. Rioux et al.'s (2016) reflection on their experience of doing research in Global South countries highlights the reasons why sensitivity to this context is essential. Another issue is the dominance of researchers from the Global North in research projects situated in the Global South – as attested, for example, by Hanass-Hancock, Chetty and Myezwa (2019) in the African context. As Katsui and Scwartz (2021) write,

> The great heterogeneity of disability and its contexts, as well as its evolving nature, mean that we must all think deeply about interconnectedness, relationality, and continuity of disability with other phenomenon across different time and space. (p. 205)

Naturally, this observation is valid for all countries – regardless of their socio-cultural and economic contexts.

The Conceptual Framework of Inclusive Research

In her book on inclusive research, Nind (2014) says that she prefers referring to "doing research inclusively" than to inclusive research (p. 92), arguing that this term avoids an idea of inclusive research as being either monolithic or static. However, despite the varied and ever evolving ways in which inclusive research is carried out, there are kindred practices and conceptual underpinnings to the type of research projects mentioned in the previous section which make them identifiable as being inclusive. The practices and research methods used are discussed in the next section, after an exploration of the conceptual framework informing inclusive research in this section.

The most important concept underlying inclusive research is an understanding of disability as being something other than the sum total of one's impairment. Within this framework, the nature of disability is understood in different ways: as standing in clear opposition to impairment as with the social model of disability (Oliver, 1983); as being in relation with impairment as with the social relational model of disability (Thomas, 2004); or as being a concept that needs to be critiqued alongside the notion of impairment as with critical disability studies (Vehmas & Watson, 2014). These and other models of disability complement each other by distinguishing between disabling barriers and impairment, even if the nature of the two and the relationship between them are contested to different degrees and in different ways. What is important is that the distinction is made and applying it to intellectual disability enables addressing the contextual barriers that persons with intellectual disability encounter in the research process, rather than attributing the cause of the difficulties they experience solely to the presence of cognitive impairment. This is not to say that the presence of impairment and its potential effects are ignored. On the contrary, it means that measures are put in place to cater for impairment-related limitations. Thus, persons with intellectual disability are conceptualized as being able to engage in all stages of the research process – from planning through to implementation and onto dissemination of results – once the required support is in place.

In this regard, the concept of "relational autonomy" can be seen as an inherent component of the conceptual framework of inclusive research, even if it is not used explicitly by those writing in the area. Davy (2015) calls for a conceptualization of autonomy "as enabled relationally, through a network of relationships that require support and advocacy, rather than as a status or psychological attribute" (p. 146). The relationships forged in the process of conducting inclusive research fit very well within this concept, since persons with intellectual disability are provided with support to engage directly and actively in the research process and barriers to their doing so are addressed. As Davy (2015) explains, relational autonomy “captures the notions of interdependence and ongoing support” (p. 146). These notions apply to inclusive research as well – the different actors involved in such research are dependent on each other as they engage in different and complementary roles, with the academic (or other) researchers providing support to coresearchers with intellectual disability in the process of conducting research together. In fact, Nind and Vinha (2014) place support, negotiation, and interdependence at the center of inclusive research.

Another important concept underpinning inclusive research is that of knowledge being (at least partly) experiential in nature. The knowledge that persons with intellectual disability bring to inclusive research, which they have acquired through their lived experience, thus plays an essential part in inclusive research. In fact, coresearchers with intellectual disability are referred to as “experts by experience” by some authors (see Embregts et al., 2018; Vega-Córdova et al., 2020). The lived experience of coresearchers can – and should – inform all the stages of the research process, starting from the choice of research topic. From my own experience, I appreciated the importance of this when – in relation to the research on overprotection mentioned above – I first discussed with my coresearcher what we should do our research on. She immediately mentioned overprotection, a subject that I had not thought of but which is important for her and other persons with intellectual disability that she knows.

The dynamic nature of inclusive research, the attention given to socially constructed disabling barriers, and the importance placed on expertise gained from experience and on the relationship between those involved in conducting research place inclusive research within the interpretive research paradigm. As explained by Corbetta (2003), in interpretivism, reality is seen as knowable through the meanings attributed to it by different individuals. Consequently, what is seen as researchable is not the objective nature of a particular reality, but the subjective interpretations attributed to that reality by those who live it. Given these ontological and epistemological standpoints, the research methodologies used are ones that promote interaction between researchers and researched. As with participatory research, inclusive research goes even further by adding a researcher role to those (or at least some of those) who are researched.

Inclusive Research Methods

The interpretive paradigm in which inclusive research is situated means that it is qualitative methodology that is usually employed. There are some exceptions where quantitative methods have been used within projects that have been conducted inclusively to different extents. For example, Walmsley (2015) reports on research by Emerson et al. (2005) in which adults with intellectual disability helped to develop methods and questioning techniques that were accessible and also to ensure that the results of the survey conducted were presented in an accessible manner. The research that Sample (1996) reports on used a mixed methodology.

Most other inclusive research projects use a qualitative research methodology, thus involving meetings with people. The types of meetings and the people concerned vary according to the nature of the project. For example, many of the projects mentioned earlier in this chapter through which persons with intellectual disability were supported to construct and write their life stories entailed meetings between these persons and those supporting them. There are also other projects – including some referred to above as well as others such as the one reported on by Mooney, Rafique and Tilly (2019) – in which the persons with intellectual disability involved were both coresearchers and the research participants themselves. In other projects, the research participants were not the researchers with intellectual disability and they were involved in different ways – for example, meetings with self-advocacy groups (Williams, 1999), interviews (Frankena et al. 2019), and focus groups (Callus et al., 2019). The input of persons with intellectual disability and other researchers in these studies varies. Bigby et al. (2014) identify three types of involvement of the former: as advisors, as the ones leading and controlling the research, and as part of a collaborative team.

In the research on overprotection, the coresearcher and I worked as a team in all stages of the research. At the planning stage, we both made suggestions which we discussed. We also carried out the fieldwork, transcription, and analysis together. I took care of the literature review and applying for ethical clearance. There were also areas where I provided guidance for the coresearcher, for example, in how to conduct the focus groups, do the transcription, put together the analysis, and present the research. We carried out this research collaboratively after working together on other projects in which I was more in control. Moving from one type of involvement to the other can therefore also be an evolutionary process as those involved in inclusive research gain more skills and experience.

Providing Support in Inclusive Research

An essential part of inclusive research is making the different stages of the research process accessible to the researchers who have intellectual disability. Providing accessibility in this context broadly means that the members of the research team who do not have an intellectual disability provide support to those who do. In fact, inclusive research poses challenges for those providing support to persons with intellectual disability to find the right balance between ensuring that the necessary support is provided without taking control of the process themselves.

An important area where support is needed is to ensure access to information. Since most publications are not written in easy-to-read language, persons with intellectual disability do not have direct access to information and are therefore rarely in a position to decide which information is relevant and how to make it accessible. It is left to those who can read and understand such information and, very importantly, know where to look for it, to decide what to render in an accessible format and how. Cobigo et al. (2019) discuss access to recruitment letters and consent forms for persons with intellectual disability. While their focus is on the latter as research participants rather than coresearchers, what they have to say is also relevant for inclusive research. They note how they decided what information to include in the accessible versions of these documents and what to leave out. The process therefore inevitably entails interpretation. In fact, Williams (1999) observes how as an inclusive researcher she often acted as an interpreter for the self-advocates she was doing research with. Furthermore, even when written information is provided in an easy-to-read format, access for all persons with intellectual disability cannot be automatically guaranteed since many of them may still need support in understanding what is written (Oldrieve & Waight, 2013).

Persons with intellectual disability also need support with devising a research plan and implementing it, analyzing data, and writing up and presenting research results. One of the most important issues is that those supporting coresearchers with intellectual disability need to be wary that they provide guidance where it is needed without exerting control, even if unwittingly. On a personal level, I find Hanna's (1978) image of the balance-beam – in relation to providing support in self-advocacy groups – very useful as it depicts how one must find the right balance between providing the right kind and the right amount of support that is neither too little nor too much. As I argue in Callus et al. (2019), being reflexive in the practice of inclusive researcher, being attentive to questions that need to be asked, and seeking answers to them are very important.

The issues that these support needs give rise to have been well discussed in the literature on inclusive research since its inception. For example, Williams (1999) discusses her role as academic researcher providing support to the Bristol Self Advocacy Group. She is honest about her own influence over the group (for example, being the one to suggest that they do research) and her access to information which is often beyond the reach of persons with intellectual disability. As she writes,

> most of us do have the advantage of being able to read research journals, books and other literature. We also go to conferences and meet other researchers; we might work in centres where other colleagues can be consulted quite easily. (Williams, 1999, p. 49)

Williams also discusses the method used for data analysis, pointing out that making this process accessible means that more time than usual is needed for this stage. The issue of needing more time to carry out inclusive research is also mentioned by Embregts et al. (2018). Stevensons' (2014) article about the process of analyzing data in a collaborative manner with coresearchers with intellectual disability is a clear example of how this process can be facilitated once there is enough time allocated to it.

Issues regarding data analysis do not rest only with how it is done and how long it takes. The process of discussing the data beyond the immediate experience of the researchers with intellectual disability is also considered. Williams (1999) argues that persons with intellectual disability do engage in such processes:

> If a theory is broadly taken to be a model that helps us to understand why things are as they are, then self advocates do engage in theory building incessantly. For instance, the theory that labelling influences people's thinking is a very powerful one. (p. 51)

This position is also taken by Roets et al. (2005) in their discussion of how self-advocates could reflect on their life experiences and consider social factors impacting those experiences. Labeling is one such factor, and they quote Patrick Scheflhout, a self-advocate:

> I find the word 'mentally retarded' a pityful [sic] word. It's made up by them to put a stamp on your head – you're simply not able to do one thing. I don't think they are right. I find out it only is a label – to make you stay where you are. (Roets et al., 2005, p. 106)

However, there are also levels of theorization that are inherently difficult for persons who have intellectual disability to achieve because of the cognitive limitations experienced (Schalock et al., 2021). This situation creates dilemmas for academic researchers. For example, Walmsley (2001) draws from her own experience of working together with other academics and with women with intellectual disability on a book about the women's life stories. The academics wanted to bring in feminist and disability theories to bear onto these stories, whereas the women with intellectual disability "wanted the stories to speak for themselves" (Walmsley, 2001, p. 198). While this group of researchers were able to compromise, others find it difficult to do so especially when persons with intellectual disability are involved in research projects which are also the PhD project of the researcher providing them with access and support. This was the case, for example, for Williams (1999), Björnsdóttir and Svensdóttir (2008), and McCulloch (2011). Walmsley (2001) also makes the point that not engaging in theoretical discussions about the findings generated by inclusive research project can risk holding back its development.

The ways in which the issues and challenges discussed here are tackled to ensure that inclusive research is carried out effectively depend to a large extent on the competencies of those involved. In this regard, the research by Embregts et al. (2018) is very useful because it throws light on the competencies that are needed for people with and without intellectual disability to engage in inclusive research. Some of the competencies are needed by both – building a mutual relationship, communicating, and being adaptable and flexible. Then, those who do not have an intellectual disability need to be able to respond to the support needs of persons with intellectual disability. The third set of competencies are relevant for persons with intellectual disability, including the ability to learn and develop and the ability to ask questions and to reflect.

This last set raises a perennial issue faced in inclusive research – the tendency for the persons with intellectual disability involved in it to be ones who are articulate and do not have high support needs. The inclusion of persons with severe levels of cognitive impairment is a challenge that has yet to be taken on. One of the main challenges is that of communication. Even involving persons with communication difficulties as research participants can be challenging (Nind, 2008; Valade, 2004).

This is not to say that there cannot be other ways of doing inclusive research that are better adapted to those with communication difficulties. But it certainly is an area that needs to be developed.

How Inclusive Research Is Written About

There are potentially as many publications presenting the results of research projects conducted inclusively as there are publications discussing how the research was conducted and written about. Broadly speaking, the latter tend to be written by academic researchers for peer-reviewed publications, including a significant proportion of the publications cited in this chapter. The former tend to be cowritten with persons with intellectual disability and published in easy-to-read formats as research reports. This twin track responds to the dilemma discussed above about keeping writing accessible – and therefore outside what is usually expected for an academic publication – and developing inclusive research and its output conceptually within academia – with the result of making it largely inaccessible for those who have intellectual disability. Publishing inclusive research findings accessibly and discussing inclusive research methodology academically are a way of dealing with these two demands.

Academics working within the inclusive research paradigm are well aware of the paradoxical situation they find themselves in when they do not write in an accessible manner (this chapter being itself one such instance). For example, Walmsley and Johnson (2003) explain why their book on inclusive research is not targeted at persons with intellectual disability. They felt that they needed "space to air arguments and debates before attempting to "translate" them into accessible formats" (p. 15). Williams (1999) and Björnsdóttir (in Björnsdóttir and Svensdóttir (2008)) both tackle the issue of not being able to make their PhD work accessible because of academic requirements.

There are also collaborative writings in academic publications. For example, Björnsdóttir's coauthor is a self-advocacy group member. Other examples of such collaborations cited above are Roets et al. (2005), Walmsley and The Central England People First History Project Team (2014), Callus et al. (2019), and Mooney et al. (2019). With the exception of the latter, the lead author in these publications are academics. Such publications usually also have a section describing the different roles played by the authors in the writing process. They are then often complemented by non-peer-reviewed publications where the lead author is a person with intellectual disability. To return to the example from my own work, the coproduced article published from the research on overprotection in an academic journal (Callus et al., 2019) has a parallel more detailed report of the research findings written in a more accessible manner as well as an easy-to-read summary (in both Maltese and English) (see Bonello and Callus (2017) for the report in English). A similar strategy was also used by Nind and Vinha (2014), two academic researchers who, apart from the peer-reviewed article, also published the full report on their analysis of doing inclusive research (Nind & Vinha, 2012). Apart from having the advantage of allowing for both accessible and academic types of writing, this practice enables researchers with intellectual disability to take the lead in some of the publications and provides documentation that is accessible for other persons with intellectual disability. Much of this documentation is published online, and in this regard, the Internet has made it possible for accessible research reports to be published and disseminated widely since they are also open-access. Moreover, this enables the publication of research reports in much greater detail than is ordinarily possible in peer-reviewed articles.

There are also articles written in easy-to-read language in peer-reviewed publications. One notable example is Docherty et al.'s (2005) chapter in Goodley and Van Hove's *Another Disability Studies Reader?* Another is the 2012 special issue of the *British Journal of Learning Disabilities* on "Research and work of people with learning disabilities and their allies and supporters" in which not only are the articles coauthored with persons with intellectual disability, but also the peer-review team that edited the issue was comprised of academics and researchers with intellectual disability.

Conclusion

The development of inclusive research is strongly tied with the disabled people's movement, especially self-advocacy. Within academia, it is connected with the evolution of participatory research and emancipatory disability research, which have enabled those who were once the passive (and even unwitting) subjects of research to set research agendas and carry out research themselves.

Inclusive research has developed into a unique way of doing research, especially through the way that professional researchers support persons with intellectual disability while simultaneously conducting research with them. Inclusive research operates within a recognizable conceptual framework which sits well within the interpretive paradigm of social science research. Most inclusive researchers use qualitative methodologies, with variations in the types of methods used and the respective roles of researchers with and without intellectual disability. One of the issues faced by the latter is how to provide the necessary support for coresearchers with intellectual disability without exerting control over the research process, especially since they are the ones with access to the relevant information and with professional experience in conducting research.

When it comes to publications, those involved in inclusive research seek a balance between publishing in a nonacademic accessible manner and using an academic nonaccessible style. Quite often, this balance is found by having research reports using plain language (usually published online) and peer-reviewed publications which usually discuss the processes used to conduct the research. Researchers with intellectual disability usually take the lead in the former.

Since its beginnings in the 1990s, inclusive research has developed considerably. There are also continuing challenges for it to deal with, most notably the involvement of persons with intellectual disability who have communication difficulties or high support needs and the use of inclusive research methods in the Global South. The fact that inclusive research has a coherent conceptual framework while at the same time affording a high degree of flexibility in how it is conducted augurs well for developments that can meet these challenges in an authentic manner.

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Whose Vulnerability? Challenges in Conducting Participatory Research with Children with Multiple and Complex Disabilities

Eduarda Sousa Pires

Contents

Abstract

Research on disabled children with complex and multiple disabilities is still recent. In the quest to reach out these children voices researchers have turned to participatory research and to the mosaic approach.

The advantages of exploring the Mosaic approach are to grant researchers with multiple and flexible tools which can intentionally be designed and adapted to reach each children voice enhancing their agency. However, in this process and when pursuing inclusiveness, researchers face some additional challenges. This chapter will bring into discussion some of those challenges found in the practice of researching with 52 children with multiple and complex disabilities, during a program of Animal Assisted Therapy sessions held at four different school settings.

During the ethnographic research, the challenges associated with the practice of researching in this context of mix (dis)abilities showed that children participation, namely, on tool design, turned out to be a process of co-researching.

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It is suggested that a better understanding of the process and the procedures of co-researching with children with multiple and complex disabilities, and in contexts of mix (dis)abilities, should consider the different dimensions of vulnerability enacted by the research situate encounters.

Keywords

Participatory Research · Disabled children · Mosaic Approach · Research tools · Animal Assisted Therapy · Reflexivity · Vulnerability

While research on disabled children is still recent (Stafford, 2017; Wickenden & Kembhavi-Tam, 2014), there is a growing body of literature drawing from children's voices and perspectives about their own lives (Rogers & Boyd, 2020). However, most of this research addresses children from the perspective of their specific impairments. Contemporary *childhood disability studies* (Goodley & Runswick-Cole, 2011) call attention to the fact that children with complex and multiple disabilities are not a homogenous group but rather present a diversity of identities. The fact that they are almost absent from research increases their invisibility, which is compounded by a general perception about their lack of agency and inability to perform an agentive citizenship (Wickenden & Kembhavi-Tam, 2014).

There is an increasing recognition of the need to bring the diversity of disabled children voices into research and to include their perspectives alongside of those from the ones of other children. By capturing their agency and individuality (Goodley & Runswick-Cole, 2012), research will be enriched by their disability-specific experiences and views (Wickenden & Kembhavi-Tam, 2014). Still, for the purpose of enabling these children's voices, researchers need to use innovative methodological approaches which is inspiring researchers to make use of participatory methodologies.

Participatory research has, indeed, been central to multimethod qualitative research (Mockler & Ground-Smith, 2015; Raffety, 2015; Coyne, 2018) and largely adopted by researchers wanting to focus and understand children as social agents and experts, while acknowledging their voices and forms of expression (Goodley & Runswick-Cole, 2012).

Hereby, in the process of conducting a research co-constructed with children with multiple and complex disabilities, the researcher has resorted to the Mosaic approach – a participatory research method, with the aim of capturing the representations and meanings of disability and exploring if the context of Animal Assisted Therapy (AAT) sessions could enact children's different (un) becoming's (Davies, 2018).

The Ethnographic research took place in four school settings, with four different groups of children involving a total of 42 children aged 9 to 16 years old. The empirical data was produced over a 9-month period, in the context of an Animal Assisted Therapy (AAT) program designed to offer therapeutical and educational skills support to children with multiple and complex disabilities.

In the process of researching, several factors were found to be key regarding the access of children's voice and their voluntary and meaningful participation. Thus, the aim of this chapter is to highlight and discuss some of those critical elements that challenged the design and practice of the research, as well as describing the handed processes in dealing with them. The discussion will start from the description of the research participatory approach, the tailoring of its methodological tools as a co-creative process, to the key challenges faced during the research course and how researchers delt with them through reflexivity and a reflexive practice. Discussion will engage into the concrete research examples and some of its ethnographic episodes. By doing so researcher expect to foreground the challenges faced during the research course but, at the same time, to bring an understanding lens from the situated process of co-researching with children and from where knowledge was extracted from. This lens will also bring into the discussion the multiple dimensions of vulnerability observed while researching.

Overall, the discussion here presented is expected to contribute to a better understanding on the process and procedures of co researching with children with multiple and complex disabilities in contexts of mix (dis)abilities.

Edging up the Mosaic Approach for a Participatory Research

The Mosaic methodology is better described as an approach as it encompasses a set of multiple methodological tools that enable qualitative data production. Since it is intentionally designed to enhance children agency and voice, it presents an opportunity to the inclusion of children in participatory research.

The advantages of exploring the Mosaic approach (Clark, 2011b) grant researchers with the possibility of using multiple flexible tools for the participatory research with disabled children. Bearing in mind that disabled children make sense and think about experiences in diverse ways, taking the Mosaic approach into practice provides a way to pursue research inclusiveness – where participants can become co-researchers, be experts, and make meaning out of the experiences of their own lives (Clark, 2011).

The variety of qualitative methods and methodological tools can include narratives, physical or visual expressions, and others, which in the end are brought together to create a whole meaning picture (Rogers & Boyd, 2020). And, the access of children's perceptions and views is determined by the research contexts (Greenfield, 2011; Wilkinson and Wilkinson, 2020, p.7).

During the process of the research here reported, the methodological design included a variety of flexible tools drawn out from the Mosaic Approach (Clark & Moss, 2005; Clark, 2011). Data was also produced through ethnography – involving participant observation and fieldnotes, writing and analyses, as well as photo capturing, and a multi-method data production approach was followed.

The Animal Assisted Therapy sessions took place once or twice a week in the special education classrooms. Group composition were as follows:

Group 1: six boys – 9 to 10 years old. Children impairments include autism, Down syndrome, cognitive deficit, with one child being nonverbal and two others being semi-verbal.

Group 2: three girls and three boys – 11 to 14 years old. Children impairments include Down syndrome, severe cognitive deficit, severe cerebral palsy; Prader Willy syndrome, with two children being semi-verbal.

Group 3: six girls and eight boys – 12 to 16 years old: Children impairments including autism, Down syndrome, cognitive deficit, Prader Willy syndrome, with one child being semi-verbal and one nonverbal.

Group 4: six girls and nine boys – 12 to 15 years old: Children impairments including autism, cognitive deficit; severe cerebral palsy; Lobstein disease; Down syndrome, with one child being semi-verbal and one nonverbal.

The literature drawing from the Mosaic approach draws from data produced through several resources with no predefined path available (Clark & Moss, 2011), a process requiring researchers to engage in a reflective process when developing the methodological design of their studies. As so, the Mosaic approach allowed the present research with the possibility to develop and include a repertoire of tools, flexible enough to address the practice of a participatory research facing children's diversity and needs as well as their complex and multi disabilities. These tools were aimed to create experiences that could elicit children's voices, either individual or in group. Children's feedback about their experiences regarding the use of the methodological tools was incorporated on its adjustments and often gave place to an interactive process of co creating multiple new tool formats.

The initial period of research served as a period of familiarization helping both parties – children and researcher – to get to know and understand each other. Following the opportunities to voice children's ideas – individually or in group – were progressively shaped through an open selection of tools: Wall Journals; Accessible Reading Books; Crafts; Talking cards; Story Games; Photovoice; Photo Descriptions; Photo captions; Crafts | Drawing | Painting; Rag Dolls; Play-based Dog Training Activities; Tournaments; Board Story Making; Group Puzzles; Tangrams; Emojis.

Overall, the design and the implementation of the Mosaic methodological tools was a profound relational experience. The process of research tool selection and (re) design was a continuous learning process and research also resulted from a mix of the field observations, the dialogues, and the ethnographic encounters between children and researcher. Ensuing is a presentation of the methodological tools which attracted the most of children interest and participation during the research sessions:

Photovoice: children revealed a great understanding of mobile phones and their use as photo cameras. This was a well-accepted activity that provided lots of information about children's views, feelings, and experiences on the world around them. Children's voice(s) were elicited by asking them to take photos about: "your friends and things they can do"; "how you feel when you are with us"; and "what's the best thing about being here"; and then by talking through the photos with them so to understand their meaning of the photos. Looking at the photos after they have been taken was also a moment for a "I – you" (children to children or children to us) communication.

The following are excerpts from the typical dialogues that would emerge:

Fig. 1 Photovoice

R *What are you taking photos of?*
Mauro *My girlfriend!*
R *Oh I didn't new Teodora*[1] *was you girlfriend!*

Fig. 2 Photovoice

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[1] To preserve confidentiality and anonymity all names used in this chapter are pseudonymous.

R	*How do you feel when you are here with the dogs? AH!! Like that? Wow!!! Happy? And is that because of Sam (dog)*?
Dennis	*No, it's because of him, I'm playing with him (pointing to his friend).*

(Fieldwork diary | District School 05.21)

Photo Descriptions and Captions: visioning photos brought by the researcher to the session was another activity with great acceptance among children. This tool allowed for some brainstorming and dialogues around disability and the representations of their self-disabilities.

This is better understood following this passage of the researchers field diary and illustrated by Fig. 3.

Fig. 3 photocaption

> Today children from this group were showed some photos of other group of children that are unknown to them but were playing the same dog games as they usually do. They were asked to identify what were the other group of children doing. Then followed another photo and the presentation of a single unknown child: "This is João and he is from a school in Cascais. He does not speak verbally so who can guess how he has asked the dog to sit?" And this granted the exploration of dialogues around children's ideas about disabilities.
>
> "(. . .) Machal (ASD, 15 YO) - I like pittbulls!

R	Do you?
Machal	yes!
Teacher	we are not talking about dogs we are talking about a child!
R	Yes, a boy! His name is Pittbull or PIPO! He is in the Autism Spectrum Disorder. Nuno follows his Chanel on Pipo TV.
Machal	He is autistic?
R	Yes? How is it to be autistic, Machal?
Machal	It's someone who is crazy!
Bianca (Lobstein disease 15 YO)	No, it is not!
Teacher	So. . .so Machal, are you crazy?
Machal	Me? No! Not me! And Autistic people are mean people!
Bianca	No, they are not!
Machal	Yes, they are, I've heard about it!
Teacher	Then are you mean? You are in the ASD! You and your best friend, Rodrigo! (. . .)

Bianca	Autistics are not mean. . . they just. . . are not . . .
Machal	. . .they are not aware of what is going around them!
Bianca	In my other school there was a boy that was always hanging around in the playground. I used to ask my mother why and she explained me that ASD children prefer to live in their world.
Teacher	Very well, Bianca!
Bianca	They are not aware of what is going around them! Once that boy gave me a slap.
R	And here your ASD friends, how are they?
Bianca	they are not mean people! They like to live in their world! Nobody here remembers Joca?
Teacher	Ah. . . Joca? From a few years ago?
Bianca	Joca was from their (Machal and Rodrigo) class. He had a hand which was always swollen because he bit his hand here (pointing to pulse)! He was not aware of what he was doing, he only wanted to be left alone!
Teacher	Yes, but now we have other ASD children here! Look here at Machal!
Machal	I'm not autistic (strongly said)!
Bianca	Some autistics don't speak!
Teacher	Yes, Joca didn't speak!
R	Machal, you are not autistic because you can speak?
Machal	Yes. . .. but sometimes I don't say anything!"

> By the end of the session, I told one of the teachers that it was interesting to listen children's opinions about disability and she confessed herself extremely admired as children had never had that kind of conversation, especially in such an open manner, with them.
>
> (Field Diary | Valley School -.12.21)

So, this methodological tool – presenting children's photos and asking them to produce their descriptions or captions – were able to elicit relevant and detailed information, rich descriptions, and to develop group discussions.

The dialogues were also promoted via other means, for instance games, as in the following example: "Let's all close our eyes. David, would you like to be the one describing this photo? (Then, David had some time to describe the photo to his peers) Now, open your eyes! From these five photos find the one that fits David's description!" In other occasions, the researcher could be the one describing the photo over a hide and seek game.

Talking Cards: A wide selection of card images showing scenes from different topics, were produced during research with the aim of making children "talk" about themselves – for example, their wishes, likes and dislikes, how they felt in specific situations, what would they prefer to do if able to be left home alone, and so on.

Fig. 4 Talking cards

Succeeding children visioned and selected significant cards thus generating individual and group discussions and brainstorming’s by – pick a card and answer: e.g., if I lived alone with Sam (the dog) I would: CARD – dress myself alone; CARD – I would like to go to school alone; CARD – go on holidays with friends, and so on.

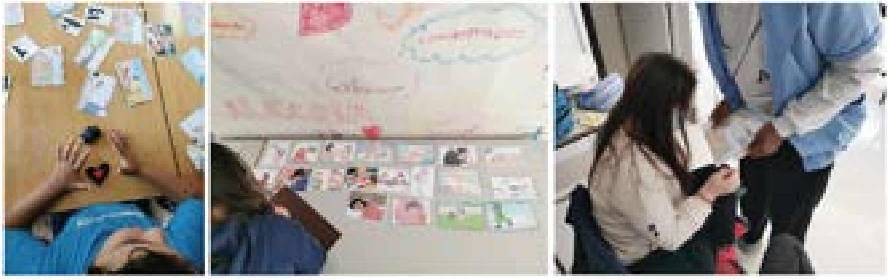

Fig. 5 Talking cards

Reading books: Group reading of cognitively accessible books – books in braille, with pictograms, audiobooks – allowed children to talk about their perceptions about impairments and differences.

Fig. 6 Reading books: group reading of cognitively accessible books – braille, pictograms, audio – allowed children to talk about perceived differences. There were no blind children in any of the groups we worked with, so we used the exploration of Braille to elicit discussions about who are the people that see with fingers? What is it to be different? Do you know any one different in your school?

Fig. 7 Superheroes

Superheroes: This tool were set up by gathering of a collection of popular superheroes images to sparkle children discussions about themselves. In all school contexts, the AAT sessions were regularly co performed with the help of three dogs. Children identified a superhero with one of the dogs and engaged in discussion prompted by questions such as: “What’s your favorite superhero?” “What superpower he/she has?” “When you are with dogs in the sessions, which superhero are you?” “Choose a superpower for you and one for the dog. What would you do with that superpower?” These and similar questions enabled discussions with children, as exemplified by the following examples:

> (. . .) I want to be invisible, and I want to cure people(. . .)

R Why do you want to be ladybird? Maggie: Because I want to fly and go outside! (Pointing to the window)

R And where is outside? Maggie: Outside away from here, this classroom! I want to go outside of here! (. . .)

> In today’s sessions all children said they would like to have the power of flying!(. . .) (Fieldwork Diary | P. School |- .03.21)

Fig. 8 Classroom boards

Classroom Boards: After a few sessions, children were asked to evaluate the routine session activities. Usually doing so by selecting appropriate emojis (happy | not happy) that would express their feelings. In these routine, children came out to be ready to co-plan the next sessions expressing what activities they would like to perform and repeat. This elicitation of children’s voices could also be done by asking them to pick up cards, showing them pictograms, and stimulating verbal discussion, among others.

Fig. 9 Rag dolls

Ragdolls: To bring the topic of difference forward and onto conversation researcher combined the use of rag dolls with other existing games. The interaction with the rag dolls could differ depending on children characteristics and needs, children groups, and the school contexts. Altogether children would be asked to choose and name a rag doll and to imagine how would it be being like – "that rag doll." Questions could come around: "Do you know someone like this rag doll? Is any of your friends like this rag doll? How do you think the blind rag doll feels like?"

Rag dolls supported researchers' exploration around children's perceptions on their lived experiences and understandings of disability and difference, as these excerpts from Valley School AAT sessions activities show:

> (. . .) Today we all went outside! Following the game explanation and the Dolls (Rag Dolls) presentation each group of children were asked to choose and name one. Nuno is always taking care of Joca (wheelchair user) and has chosen the wheelchair ragdoll! Joca after observing the doll was very happy and smiling. I asked him: are you choosing this one because Joca is in your group? Nuno said: Yes! Nuno always does this – if Joca has the wheelchair braked he goes directly to release him so he can move and be able to join session activities by himself! All children choose and elect a favourite ragdoll and I noticed that the blind doll was not chosen and was actually put aside. Initially, I thought this would be a favourite one because it included a guide dog with the doll. I asked Machal: Do you want this one? Machal replied: No, not that one! I asked another child: Lia, and you, do you want this one (picking up the blind ragdoll) Lia responded: No! I don't want it too! Curiously, none of the children choose the blind doll. Later on the phone with the coordinator teacher, whose husband is blind, I mentioned this – "Children choose all the rag dolls even the one with the wheelchair . . . but they did not choose the blind doll! She said: Well, we all know this, don't we? Everything that is different, we already know how people react to that. . . (. . .). (Fieldwork diary | Valley School. 04. 21)

> (. . .) There you are, now you have a ragdoll! Now you can have someone to talk to! Said Luisa (staff – education helper). I asked: She doesn't have anyone to talk to? Luisa explained: She sleeps a lot and cries a lot . . . and this wheelchair is heavy, so she doesn't have anyone to talk to!(. . .). (Fieldwork diary | Valley School. 04. 21)

These ethnographic conversations around ragdolls were able to produce rich data adding new insights that helped to get to know and understand better the reality of these children's lives.

Story Making | Secret Friend: Classroom boarding games were able to promote group focus and discussions around a topic. Because children were always so interested in dogs, discussions were primarily elicited by talking about dogs. The game could be asking a child to volunteer and leave the classroom. The children remaining in the room would select and identify a dog feature, which would be written down on the board. Then the volunteer returned and a find out game would be starting. For example, someone could say: "Sam likes to eat and knows how to do a lot of tricks, but he cannot go between legs, which dog is it?" Next, children would be asked to describe a selected peer.

Fig. 10 Story Making

Story Making: Story making as a good source of information about children perceptions of the different situations of their daily lives: routines; difficult situations, favorite things and so on. In some stories, the characters had an impairment so to try to elicit children's views on how it is to handle impairments in daily life situations. This instrument enabled the creation of narratives bringing out issues around disability perceptions, as this following note reveals:

> (..) Today's story was interesting! A girl lost her shoe, and she would like to find it but she could not run because she could not see well. It's very interesting how blindness always emerges as "the disability" (. . .)! (Fieldwork diary | P School 05.21)

Fig. 11 Crafts

Crafts | Drawing | Painting – Craft making, drawing or painting created moment (s) for the researcher to join in group talks and listening to and asking questions to the children. Drawing material was always at hand for children spontaneous use. The focus was on getting children's discussing their work and to achieve a co-constructed interpretation, as this dialogue with Sandro a 13 years old boy from P School illustrates:

> (. . .) R: Wow you did a dog! Is it a dog, Sam? Sandro: No. . . it's my dog! R: Oh, how nice! And your dog only has one eye? Sandro: Yes! He is disabled!! R: Ah! And how is it to be disabled? Sandro: So. . . it's to be special! (. . .). (Fieldwork diary | P. School 05.21)

Fig. 12 Painting

The activities were also an opportunity for children to express their opinions as this field note demonstrates:

> (. . .) Today Bianca came in late. She joined us painting Sam silhouette. After seeing her choosing the blue colour I told her - that's blue! This dog is Sam and he is brown and white! Bianca: Yes! But I paint as I wish and with the colour I like! R: Yes, that's true, and you like blue? Bianca: No, I just like painting as I wish! When we were finishing the teacher asked me: How did it go? I said: Very well! Bianca even told me she liked painting as she wishes and likes. The teacher was extremely surprised saying: - Wow! She usually never says anything on her own behalf! (. . .). (Fieldwork Diary | Valley School Valley School | 02. 21)

Fig. 13 Dog Training Games

Dog training tournaments – dog training games and dog training play-based activities was the more accepted activity in AAT sessions, and were transformed in a methodological tool. Throughout the AAT sessions children learn how to train dogs to perform a sit, a stay, weave between one's legs, play dead, and a few other behaviors. Training dogs served as a milieux for play-based interactions that could simultaneously develop skills (e.g., motor coordination; communication; body balance) targeting therapeutical goals and at the same time engage children in tournaments or play-based activities consenting researcher to ask, observe, and generate discussions as, for instance: asking children to choose a team, then to characterize its members, and to elect what each one would like to train related to their impairments and skills, enabling new insights into the research questions as the following passage of the fieldwork diary can demonstrate:

> (...) Today I gathered children by groups and asked them to choose a dog and a name to their groups! Then I asked them to say what special things their dogs could do and what special and different things they can do (...). It was an extremely well accepted activity! The children discussed how they are and negotiated their meanings between peers. Bianca said: "Rodrigo said he is strong like Sam (the dog) but he is not strong! He does not help anyone at lunch time! (...)". (Fieldwork Diary Valley School | 05. 21)

Children's relation with the dogs was a lens to observe the interactions and inform the research with discussions upon topics of autonomy, self-representation of disability, and difference.

Challenges of Participatory Research

The research context – the ATT sessions – was extremely important to the research and to implement and (re)design methodological tools. AAT sessions were deeply appreciated by children and provided researcher with the opportunities for interactions in a play base mode thus easing up the process of gaining trust and of achieving a close relationship with them.

Nevertheless, when implementing the participatory tools of the Mosaic approach into already existing contexts, researcher needed to face some challenges that modulated and drove the course of the research, namely: how to open the field and how to address the challenges associated with researchers positionality; how to negotiate the observation and children's participation; deciding how and when to implement the mosaic approach; the challenges created by the gatekeepers and the impact of researchers double role as therapist and as a researcher.

Thus, this discussion will in what follows focus and detail these challenges trying, at the same time, to show how throughout the research process researchers reflexivity helped on dealing and responding to them. Also, bringing into problematization the different dimensions of vulnerability that occurred during the research process.

Opening the Field and the Challenges of Our Positionality

Ethnographic Research took place, simultaneously, at the four different sites and was shaped by the different school experiences, the local actors, and the local contexts where children interacted (Schuelka, 2014). In the beginning, the researcher spent a small time-period just doing observation to get to know the children and their significant others in the classroom – the teachers and the staff providing classroom support. Taking the double role of researcher and AAT staff, positioned the researcher between an insider and outsider role, in an "in-betweener researcher position" (Chhabra, 2020, p.315) and therefore researchers first challenge was to learn about children's characteristics and to earn their interest and voluntary participation in the activities.

Given that the research context was the school environment, the first approach to children had to take place through gatekeepers. As AAT sessions, goals are supposed to produce therapeutical improvements, accessing children's clinical files had to be considered. Researchers first knowledge about these children was thus influenced by teacher's understandings, who mostly offered behavioral narratives framed by an educational and medical perspective. In some cases, children's individuality was reduced to a concise taxonomy of personal impairments, which were summarized in expressions like "he is very neurotic" or "she is very obsessive." Other times teachers tried to influence the AAT sessions design suggesting researcher with standard approaches for activities that they deemed would best fit children's impairments.

The complexity of children's disability experience was thus reduced to just a few dimensions, focused on body functionality (e.g., "These children (autistic) are sensorial, you need to bring activities that (. . .)"). Hence, medical diagnoses provided the researcher with the initial reference frame to figure out the type of participatory tools to use and how to adjust them to the mix of (dis)abilities in each group of children. However, to acknowledge the complexities of designing inclusive research tools researcher needed to understand children's abilities and at the same time overcome the teachers' deficit lens as their representations of children's (dis)abilities seemed to be locking them in a contextualized version of their vulnerability.

It was by gaining closeness to children that researcher became more knowledgeable about their communicative skills. Throughout the research process and by a constant reflexivity, researcher has understood that accessing children's participation and voice required a continuous process of refining the methodological instruments in order to adjust them to children's characteristics and needs, such as – Hugo is autistic and nonverbal but he is also an individual, so Hugo is shy and prefers a "I-you" communication, so I listen or watch him and then I verbalize it and ask him back: - Is this right?

Thus, researcher was required to do a continuous process of critical examination of the decisions made over the methodological adaptations and at the same time to scrutinize either its own or "others" representations, beliefs, and the ideas about disability and about children's (in)capacities, and that in some sense might interfere in the (re)designing of the methodological tools. In this point, either reflexivity and a reflexive practice were a valuable tools for research.

Coupling Methodological Tools to the AAT Sessions

Deciding how and when to implement the mosaic approach and how to obtain children voluntary and meaningful participation were key issues to the research. After a few sessions of observing children dynamics in the AAT sessions and having noticed their motivation to interact with the dogs, researcher took the decision to couple the implementation of the methodological tools with the activities of AAT sessions. Thus, a diversity of tools drawn from the mosaic approach and aiming to bring children's voice was integrated as a regular part of the AAT sessions, either as playful activities or as play-based interactions around dog training.

The interactions with the dogs served as a milieu of cooperation, among peers and with the dogs, reducing children's resistance, enacting and encouraging their participation and agency. Throughout the months, children became more and more proficient on dog training behaviors – a well-admired feature by other peers and adults and an area of these children's expertise. Considering the mix of (dis)abilities in each group and to grant each child the ability to communicate, we favored multiple and alternative modes of expressing. Children then developed informal and alternative ways of expressing themselves, using different tools and picking up the best ones for himself/herself, resulting in a self and a mutual knowledge and among participants.

Despite the (mix)abilities challenges, the research context created a socialization and friendship opportunity. An environment of similar abilities, a sense of "being with" where participants could cope with communication differences, profiting from similar experiences in an equitable space (Svendby & Dowling, 2013; Ajodhia-Andrews, 2016b). By implementing the methodological instruments integrated with the dog training play-based activities, we were able to promote independent voice, ability to take charge and to make choices, agency and autonomy, and at the same time to capture children's interests and gain their voluntary participation. As time went by, children gained confidence to choose and evaluate activities and co-plan the "next sessions activities" with the instructor.

Presenting the Mosaic methodology instruments as inclusive practices requires imaginative thinking and overcoming the strain of not knowing beforehand whether the adaptation of instruments was to be successful. Close listening to children's reactions, exploring their opinions about sessions (e.g., "Did you like to draw?" "Do you like to use the emojis?" "Next session shall we repeat this?") was a profound relational experience, offering support for the tool selection and design, which then emerged from the dialogues and the encounters in the field. In this sense, children contributed to the creation and improvement of the methodological inclusive tools proposed by the researcher and aimed to capture their experiences.

Understanding children's perspectives revealed to be critical for assessing their voice. By requesting children to share research decisions like planning next session routine, choosing the instruments, and evaluating session dynamics by using emoji's, the researcher could select meaningful tools in a process of co-researching, in which the children's expertise informed the methodology. In this sense, the adoption of participatory methods changed the nature of the relationship's adults-children and the power status of both the children and the researcher, leading the researcher to face the challenges of the gatekeepers.

Gatekeepers' Challenges

While the adoption of participatory methods changed the nature of the relationship and power status, creating greater balance between researcher and children, the researcher had still to face the challenges created by the gatekeepers. These were the special education teachers and the support staff that were present during the sessions. Quite often, their impact delayed access to children's voices, often (re) introducing power imbalances that affected children voluntary participation. At the different research sites, and throughout fieldwork, gatekeepers kept acting on different forms. Next, we present two passages from our fieldwork diary that illustrate some of the gatekeeper's exertions:

> (. . .) Today, again, it was impossible to ask children to take pictures. The teacher didn't allow it. He/She took the mobile phone and erased the pictures, saying: "If you want to take pictures, then take a pic hugging the dog! I'll take the pic! (. . .)" and then turning to me the teacher said: "Why do you give them the mobile phone? They can't take valuable pictures! (. . .)". (Fieldwork Diary | 03.21)

> (..) Children are always very enthusiastic when we arrive! They did some nice biscuits for the dogs. I said: "Wow! Thank you so much!" Maggie, whose fingers are small, accidently dropped one biscuit and she was trying to pick it up. The teacher said: "Maggie, biscuits are for the dogs, they are not for you!" All the teachers laughed! (4 teachers and 2 support staff)! "Look now she even picks dog food from the floor!!!" Maggie stopped, gave me the biscuit, and sadly went away from the group and did not re-joined us for the rest of the hour! Tito kept looking at her, also sad. I asked him: "Are you worried about Maggie?" Tito replied: "Yes, she is sad!" (. . .) (Fieldwork Diary | P. School | 04.21

Often gatekeepers interfered with children's participation by attempting to translate their voice ("What he wants to do is to comb the dog!") or controlling our information and/or interactions with the children, as in the examples below taken from our fieldwork diary:

> (. . .) Rui does not come to our sessions often. Today he asked to join the dog training game. Every time he managed to have the dog doing a behaviour, he screamed "Yeeha!" Teacher Bento came nearby, and I told him: "He is very happy because he can teach the dog!" Bento replied: "I've told you about him! He has severe cognitive deficit and a lot of problems with his peers in his regular class. He is a narcissistic and he likes to show off in here, but when he's with his peers he achieves nothing! His regular classmates do not accept him and there he can't do any task at all!" I asked: "What do you mean?" Bento replies: "Here everything is

> easy and that’s why he is showing off to the others! (. . .)”. (Fieldwork diary | P School. 05.21)

> (. . .) The teacher always interferes with the sessions, e.g., by saying things such as “put your hand here!” “Seat here!” “Hold the dog!” “Comb this way!” I think that then Francis avoids re-joining the interactions. In opposition to other children who cry, he just sits there, doing nothing and stares at the window outside. (. . .) The teacher said: “You see? All autistics are like this! They don’t answer properly and have these non-functional behaviours. (. . .)”. (Fieldwork diary | District School. 04.21)

Sometimes, teachers even attempted to control whose children got included and excluded from participating in the sessions, as these diary notes illustrate:

Fig. 14 Team games

> (. . .) The teacher asked: “Is William there?” William had been seating in the back of the classroom alone and watching his peers doing a Tangram. I replied: “Yes, he was doing nothing, and I asked him if he would like to join us and he joined this team”. The teacher said: “You can’t do it like that! You don’t know what you’re doing, he is very dangerous! He can’t join others like that!!!” I said: “Oh, I’m sorry. He looks so calm all the time. . .” T: Yes, but he explodes! R: Oh . . . so sorry I just thought he could join in and be happy to

> participate! Actually, we are almost finished, and he did it ok all the time . . . he played . . . communicated calmly . . .T: You were lucky ! You don't know how he is! (. . .). (Fieldwork Dairy | P.School | 04.2021)

> (. . .) I was not in the last session. The teacher asked Lara to split the group of students into 3 plus 3, each having a 30 min session. I asked Lara – "Why so?" She told me that the teacher argued that the group should be divided according to children's skills and disabilities. One group should have children that can achieve only sensorial information, and another one for whom we can prepare more difficult activities. (. . .). (Fieldwork diary | District School. 12.20)

Researcher have found that by increasing children's skills to interact with the dogs through dog training play-based activities, the gatekeepers' interference was reduced. As only children knew how to handle and train the dogs, the AAT sessions promoted a frame where gatekeepers were less able to interfere. This was only possible due to researcher double role in the field: as researcher and therapist.

Researchers' Double Role

Undoubtedly, researcher's double role in the research site – as researcher and therapist impacted the research. Primarily thought out as a difficult challenge to overcome it ended up being actually a facilitator and allowing to come closer to children. Our deep understanding of dog handling and dog behavior teaching during session activities helped to attract children's interest for participation. The fact that the researcher was also the AAT sessions instructor contributed to increase the acceptance of its presence, embedding participant observation on cooperation, active listening, and trust gaining (Gerard-Forsey, 2010), while reducing possible perceptions of power Imbalances and the gatekeeper's interference. Moreover, it opened up the chance to engage in co-constructed conversations by seating next to a child in a "I-You" 5 min talk, where researcher was able to capture the children's individual voices, allowing these moments and experiences to inform research practices and tools adjustment. The researcher–researched relationship was thus negotiated in the cooperative learning environment of dog training AAT sessions.

Reflexivity

Embracing a reflexive practice was useful to critically examine our decisions about the methodological design adaptations (Ibrahim et al., 2021). A central idea in Participatory Research is that participants are empowered, affecting the balance of power relations, which is therefore expected to shift (Ajodhia-Andrews, 2016). Reflexivity and a reflexive practice were significant procedures in the path to ethical decisions, as well as in trying to scrutinize representations of disability, beliefs, and ideas of children (in)capacities, that emerged either from researchers, gatekeepers or any significant others, and which could also influence and shape the research process. Furthermore, reflexivity was greatly necessary when facing the challenges that emerged from co-researching with the children, considering their (dis)abilities and diversity of ways of participating, and guided the process of constantly verifying how accessible and suitable the participatory instruments were. Disability interacts in a multifaceted way (Watson, 2012) and the researcher needs to problematize the complexities involved. Researchers' self-reflexivity helped to understand the intersections of power, researcher's role, and to address issues of vulnerability.

Reflexivity led to realize how the research practice and experience enacted vulnerability through different dimensions, not just due to the methodological challenges but also due to the interference of gatekeepers.

Whose Vulnerability?

The research field of severe and multiple disabilities presents the researcher with additional challenges related with vulnerability. Researcher initially thought to be addressing issues of vulnerability by pursuing a research praxis grounded upon informed consent and voluntary participation as ethic standpoints. However, researcher came across different dimensions of vulnerability affecting children and its ethical decisions, understanding that vulnerability could be an opaque category cross-cutting research and research subjects (Mellstrom, 2016). The inner version of vulnerability coming out of teachers' narratives about their children impairments showed that the context where individuals might be considered vulnerable can influence their becoming's. Considering the example of Teacher Bento's narrative presented above, this becomes evident:

> (. . .) Bento: Rui (cognitive deficit 16 Y.O.) is a narcissistic and likes to show off in here but when he is with his peers, he is not able to do anything! His regular class does not accept him and there he can't do any task at all! R: what do you mean? Bento: here everything is easy (. . .). (Fieldwork diary | P School. 05.21)

In Teacher Bento's words (and social representations), Rui falls outside of the categories of his peers and AAT sessions are not recognized as a context for an emancipatory participation. Rui's experience is not considered a contextualized experience, but rather a reference for judgments about his (lack of) competence, thus becoming a site for disability identification (Runswick Cole and Goodley, 2015: 9). The medical and educational deficit lens draws aspects of a vulnerability version, supporting the teacher's interpretations and disabling the child.

Another example of this came up when, by the end of a session, we saw one of the children – Manuel – with his mother walking in our direction:

> (. . .) Teacher: There goes Manuel! It's incredible as he seems to have no impairments at all when he is with his mother and outside school! (. . .) A few months before I had another conversation with the same teacher about Manuel: "R: Manuel is so sleepy today! Teacher:

> Yes, he has a new medication today... yesterday he had a big crisis he did not want to be at school he is very difficult to deal with! (...)". (Fieldwork diary | P School. 07.21)

Children's vulnerability can endorse a vision of children within a homogeneous category (Underwood, 2014; Aldridge, 2015) intercepting their visibility.

Researchers positionality and double role in the field implied a close relation researcher–researched and leading to a reflection on the nature of vulnerability (Tang et al., 2020) and how it was enacted on and by the research. Vulnerability seemed to intersect children experiences in multiple ways and dimensions, as well as researcher's decisions and research fieldwork. In the beginning of the fieldwork, teachers expressed their concerns around children vulnerabilities suggesting that researcher needed to respect children given their impairments and incapacities. "(...) This children with extreme ASD are only sensorial! You need to bring out only some sensorial activities (...)" (Fieldwork diary | District School | 12.20)

As research progressed, it became clear that refining methodological tools to be inclusive was a continuous process of giving attention to children's individual preferences for participation. This showed that the contexts where children are considered vulnerable influence their opportunities to participate in research and impact their (in)visibility. The participatory research via the Mosaic approach, tools design, and implementation created a situated knowledge experience (Haraway, 1998; Simons & Watson, 2015), shading a new light on the intersections of the different dimensions of vulnerability: vulnerability as an invisible category holding back children's opportunities to unbecome vulnerable; vulnerability as the product of the context where the research took place; vulnerability as a consequence of participatory research; vulnerability as the persistence of medical and educational gazes; vulnerability as an inner space of understanding between selves (researcher and researched).

Researcher would therefor argue that vulnerability can account for dimensions of subjectivity – happiness, joy, fear, empathy, and so on – occurring in the interactions and through the research process where children are subjects-selves, and not research subjects. Attention to vulnerability is attention to the tensions of the research practice and how these shape field interactions in the process of knowledge co-production. Taking vulnerability as a research data, resource can account for what has happened in the situated encounters between researcher and children (Abadía, 2021), the subjectivity of the relations, and how tools refinement makes a way through it:

> (...) I have to give special attention to this ... I really like Maggie. Maybe I pay her more attention and I'm more sensitive when teachers make jokes about her. (...) I guess I found a way to communicate with Vitor – he is shy and for me that's easy to understand. (...)
>
> (Fieldwork diary | P School. 03.21)

Concluding Remarks

In the process of conducting research with children with multiple and complex disabilities researcher found central aspects of participatory research. The challenges of facing the research subjects mix (dis)abilities led to search and understand how qualitative methodology could create opportunities to voice children's ideas, namely, how to shape tools and engage in field encounters.

Researcher have understood that perceiving children (in)capacities was just a small part of the overall decision path of tool adjusting for participatory research. Drawing inclusive tools was possible by taking the time to know and understand children's individualities and vulnerabilities and to pay attention to the researcher vulnerability too.

This was an open process where tool selection and design emerged from the dialogues, the encounters, and the relational experiences in the field. There were many advantages in coupling the mosaic approach with the dynamics of the AAT sessions: Enacting an opportunity to apply and develop the mosaic approach in an environment of cooperation, based on the AAT dog training activities, and where the researcher's double role made a way into children's interests – interacting with dogs, bringing forward children voluntary participation. The Mosaic approach turned the AAT sessions into a privileged research context, "outside" gatekeepers' surveillance and changing its standard nature where children are seen as passive recipients of care and of therapeutical interventions.

Reflexivity and a reflexive practice were also valuable tools. Considering gatekeepers attempts to readjust the sessions course and relationships in the field led researcher to reflect on the nature of vulnerability. How are narratives of vulnerability a lens, shaping the perceptions of children agency – as vulnerable beings and passive recipients of care – as depicted in gatekeepers' voices? How can vulnerability visions hide demeaning representations and social constructions of disability? Participatory research and the mosaic approach challenged the visions of vulnerability granting children's autonomy practices built out of their own interests.

These outcomes strongly suggest that future research directions in AAT should continue to explore the Mosaic approach and improve sessions practices by emphasizing children's active role as co-creators of their own "therapeutic interventions," outside the traditional medical approach that views them as less then or in need of being cured or fixed. This study further suggests that there is an advantage for qualitative researchers in considering vulnerability complexities and intersections occurring during research as important data. Exploring the different vulnerabilities enacted by the research, challenges researchers to unveil the dominant discourses associated with the social representations of disability.

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Qualitative Visual Methods in Research with Girls and Women with Disabilities in the Global South

29

Xuan Thuy Nguyen, Claudia Mitchell, and Tammy Bernasky

Contents

Abstract

This chapter examines how Participatory Visual Methodologies can be used to create more inclusive and accessible spaces with disabled people in the Global South. Drawing on a 4-year research project, funded by the Social Sciences and Humanities Research Council of Canada (2016–2020) with girls and women with disabilities in Vietnam, we argue that a decolonial Participatory Visual Methodology (PVM) approach is critical for centering the perspectives of girls and women with disabilities in spaces where they may have previously been excluded. This work is important for disability rights because it creates a more transformative approach to social justice in communities in the global South.

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Participatory Visual Methodologies · Decolonial · Girls and women with disabilities · Rights

Introduction

It is estimated that nearly 20% of women and girls worldwide have a disability (United Nations Population Fund, 2018). Of the world's one billion people living with a disability, approximately 80% live in the Global South, and of those 60% are women and girls (Dowse et al., 2016).

Women and girls with disabilities in the Global South experience marginalization and exclusion in all aspects of life. With lower rates of school attendance and heightened rates of bullying and violence (Women Enabled, n.d.), girls with disabilities face specific challenges to accessing education due to the intersections of gender, poverty, and disability. This includes a lack of accessible toilets, parental fears that they will be sexually abused by people in positions of power (teachers, assistants, bus drivers), and a feeling that girl's education is less valuable which is further compounded by negative perceptions of disability (Price & Goyal, 2016). Women with disabilities are excluded from work and economic activities, they face continued stigma if they want to marry or have children (Price & Goyal, 2016), and experience multiple barriers to accessing justice (Dowse et al., 2016; Bernasky, 2022; United Nations Population Fund, 2018).

Importantly socio-political contexts impact the daily experiences of women and girls with disabilities. For example, post-colonial Vietnam has centered rapid socio-economic reform; emphasizing neoliberal practices of decentralization and privatization of such services as education while also ensuring that the state continues to control and monitor the population. Furthermore, despite its rights-based language, Vietnam's Law on Persons with Disabilities has taken a medicalized approach to disability with their ranking of disability from mild to exceptionally serious, effectively formalizing the medicalization of disability within the laws and policies (Nguyen, 2016). The medicalization of disability by levels of severity also decides who gets access to services. For example, while people with "exceptionally severe" disability (*người khuyết tật đặc biệt nặng*) and those with "severe disabilities" (*người khuyết tật nặng*) are entitled to the government's social assistance, those with "mild disabilities" (*người khuyết tật nhẹ*) do not receive such benefits (Socialist Republic of Vietnam, Decree 673/VBHN-BLĐTBXH, 2019). This creates power imbalances among disabled people, thereby making it difficult for them to engage in discourses about their rights and leaving significant gaps in knowledge about the exclusion and marginalization of women and girls with disabilities in the global South.

In theory, the rights of women with disabilities are covered by all international treaties. In practice this is not the case. In a response to this historical neglect, Article 6 of the CRPD specifically addresses women and girls with disabilities (United

Nations, 2016). It also includes gender in other general rights provisions (CBM, 2013). The Committee on the Rights of Persons with Disabilities General Comment No. 3 recognizes that,

> International and national laws and policies on disability have historically neglected aspects related to women and girls with disabilities. In turn, laws and policies addressing women have traditionally ignored disability. This invisibility has perpetuated the situation of multiple and intersecting forms of discrimination against women and girls with disabilities. (United Nations, 2016, p. 1)

Conventions may lead to changes in national laws, but they do not guarantee changes in everyday living conditions for people with disabilities (Lindqvist, 2015). While the CRPD is unique in recognizing that women and girls with disabilities are at greater risk of discrimination and abuse (United Nations, 2012), addressing rights obligations under the CRPD needs be more comprehensive and reflective of their experiences (Women Enabled, 2013) that are impacted by their socio-political contexts.

In order for women and girls with disabilities to achieve their rights to education or the labor market, or to justice, they must know what their rights are, and they must also be able to recognize and express when their rights are violated. While there are different approaches to empowering women and girls with disabilities to claim their rights, in this chapter we argue that working with marginalized women and girls with disabilities is crucial to raising awareness about their rights. Furthermore, community participation and involvement of people with lived experience in ways that recognize the diverse experiences and embodiments of women and girls with disabilities in the global South is critical for their participatory engagement and empowerment.

As a post-colonial, socialist country, Vietnam has emerged from long-term struggle against colonial and imperialist wars, which impacted the ways in which the country's disability rights agenda has been developed. Specifically, while the country's post-war period was associated with a rehabilitative approach for war-wounded soldiers, this approach continued to be reinforced within the country's period of social and economic reform in late 1980s and has been morphed into the new Law on Persons with Disabilities in 2010 (Socialist Republic of Vietnam, 2010). The law, which came into effect in 2011, draws on some of the CRPD principles regarding equality and non-discrimination, inclusion, participation, and accessibility to public spaces. Additionally, the state developed social assistance plans to assist people with disabilities in health care, education, and employment. This approach, however, fails to recognize the socio-political dimensions of disability in relation to the social and political contexts which produced impairments.

Girls with disabilities have been left out of this legal consideration. While the right to education is recognized for all children, girls with disabilities encounter multiple barriers to inclusion because of their class, gender, disability, and ethnicity (Nguyen & Mitchell, 2014). Their experiences with oppression are intersectional and multi-layered, reflecting the challenges of delineating the causes of their exclusion.

Furthermore, while feminist and disability organizing has been mobilized across transnational and national stages, girls with disabilities in some of the most disadvantaged communities have been marginalized from the disability movement. Indeed, while international organizations have started to document the rights of girls with disabilities (Pearce et al., 2016; Leonard Cheshire Disability, 2017; DAWN, 2020), these approaches are usually adultist-driven and have failed to engage with the perspectives of girls with disabilities themselves.

In this chapter, we critically examine how women and girls with disabilities in the global South can use participatory visual methods to claim their rights. We draw on a 4-year research project, funded by the Social Sciences and Humanities Research Council of Canada (2016–2020) to examine the ways in which women and girls with disabilities used arts-based, community-engaged, decolonial and participatory visual research to claim their rights. We argue that in order for research on disability rights to be meaningful for women and girls with disabilities in the Global South, there is a need to engage with the lived experiences of women and girls with disabilities in their local contexts in relation to their advocacy agendas. Participatory visual research provides an important way for reframing disability rights within the context of the Global South.

Participatory Visual Methodologies

Our work with women and girls with disabilities builds on the specific area of qualitative and participatory research referred to as Participatory Visual Methodologies (PVM). These are research approaches that employ the use of visual and arts-based tools such as photovoice, participatory video and cellphilming, digital storytelling, and drawing to engage participants and their communities in eliciting their perspectives on particular social issues affecting them (Mitchell et al., 2017). Taken as a whole, they are “methods that actively engage participants in creating and analyzing visual media (e.g., photography, video, or drawings) as part of the research process” (MacEntee & Flicker, 2019, p. 352). Often framed as supporting the idea of “research as intervention” (D’Amico et al., 2016), Participatory Visual Methodologies are multi-faceted in they can act as (1) modes of inquiry, (2) modes of representation through which participants can speak out and speak back on issues that they see as critical, (3) modes of knowledge production through the co-creation of knowledge, and (4) modes of knowledge mobilization within the research processes (Mitchell et al., 2017; Mitchell & Sommer, 2016).

On the one hand, these participant-led tools and approaches contest many of the typical power relations between researchers and communities that exist in more traditional research methods and tools such as interviewing or focus groups, and as such are particularly relevant to working with girls with disabilities. How might the various media forms used (especially photovoice and video production) ensure visibility in a context where disabilities = invisibilities? On the other hand, the use of PVM approaches raises new questions about who can participate and under what circumstances. What are the physical or other barriers to engagement? We explored this in the Monitoring Rights for Girls with Disabilities (MRGD) project where girls and women with disabilities in Vietnam participated in drawing and photovoice activities related to how they see exclusion. As Mitchell, De Lange, and Nguyen (2016) argue, in a chapter exploring the ethical issues attached to this work, many of the typical ethics processes attached to photovoice (ranging from who manages the visual data to what counts as anonymity) were challenged in a generative way in the study.

The above mentioned chapter drew attention to the fact, for example, that while our Ethics Board insisted that the research team must ensure any visual data circulated have no identifying information, the girls participating in the workshop were using their cellphones to photograph themselves doing photovoice work with the cameras that had been provided. In essence the circulation of the images was potentially a concern. Interestingly, although we had discussed issues of confidentiality with the girls and their family members early on in the photovoice workshop, the girls themselves were empowered to use their cellphones to document the process and possibly share the data on Facebook. The question of power and access for the girls, then, seemed more important than the research protocols developed under very different circumstances. Our team also came be more critical of some of our own photovoice protocols such as “no faces” (Mitchell, 2011). In many of our training sessions we often will engage participants in a discussion about what they could take pictures of besides people’s faces, especially if people outside of the project participants are “in the picture.” However, we began to re-think what counts as identifiable information:

> It was only in preparation for these workshops that we began to question the limitations of a ‘no faces’ approach. First of all, why a ‘no faces’ approach [. . .] ? Where does the anonymity of the body reside? What if a participant or a photo subject is in a wheelchair? Participants might avoid taking a picture of someone’s face but the wheelchair may be a much more recognizable and identifiable marker (Mitchell et al., 2016, p. 249).

Re-evaluating research ethics protocols within the context of the research environment is critical and necessary especially as it relates to ethics in working with communities of people with disabilities.

The area of PVM has been highly generative in relation to adaptions to expand the potential for the meaningful engagement of participants, and in so doing addressing some of the various challenges, particularly around ethics and especially the ownership of the productions. The widespread access to cellphones of young people, including many girls with disabilities as we note above, has led to the idea of cellphilming (cellphone+video) (Dockney & Tomaselli, 2009) which has now been applied to a variety of contexts (Mitchell & De Lange, 2013; MacEntee et al., 2016). The refinement of tools of reflexivity and the idea of “speaking back” has expanded the possibilities for the critical engagement of participants (Mitchell et al., 2017) beyond simply making a cellphilm or taking a series of photos. The use of methods such as Participatory Data Analysis (Liebenberg et al., 2020), means that the interpretation of the data can increasingly be done through the eyes of participants and not just by the research team. As Mitchell et al. (2017) describe in their work on the development of exhibition catalogues, and composite videos and digital dialogue tools, the visual data lends itself to "repurposing" so that researchers (often in collaboration with participants) are creating video productions and digital stories as ways to reach audiences. These innovations lend themselves to the enhancement of this work as central to knowledge mobilization.

The Use of Participatory Visual Methodologies in the TDKRA Project

Transforming Disability Knowledge, Research and Activism (TDKRA) is a collaborative, community-engaged, decolonizing, and participatory research project funded by the Social Sciences and Humanities Research Council of Canada. TDKRA aims to tackle the absence of knowledge on girls with disabilities in the global South by engaging them in claiming their rights and advocating for their inclusion. We partnered with Disabled People's Organizations (DPOs) in each community to engage the DPOs in participatory research, fostering their leadership and activism, and enhancing their roles within their communities. Using PVM, in-depth interviews, and focus groups, we engaged with women and girls with disabilities in three disadvantaged communities in Vietnam – Binh Thuy and Ninh Kieu (Can Tho City), A Luoi (Thua Thien Hue Province), Bac Tu Liem (Hanoi City).

While PVM has been useful in shifting power relations between the researchers and participants, as indicated in the previous section, the use of PVM has not always embodied a decolonial perspective. In TDKRA, we use PVM as a part of our decolonizing and emancipatory approach that engages with the social, cultural, and historical conditions in the Global South (Nguyen, 2020). As Nguyen (2016, 2020) argues, a decolonial PVM approach would reframe disability in post-colonial contexts from the standpoint of the colonized. We applied PVM in each stage of the TDKRA research process to engage with participants' perspectives on inclusion and exclusion, as well as to convey their messages to their friends, teachers, families, community members, and policymakers. While some girls had experience with photovoice from their participation into our pilot project in Bac Tu Liem (Mitchell et al., 2016; Nguyen et al., 2015), many had little or no experience using PVM to produce knowledge or foster activism with their communities.

In our research, tensions arose between a rights-based approach embedded within the UNCRPD and a decolonial approach which centralizes the voices and perspectives of participants in the global South. We found that although the DPOs with whom we worked had mobilized disability rights in their activist agendas, the language of rights was not always accessible to girls with disabilities and their community members (Stienstra & Nguyen, 2020). Participants tended to express their basic needs, such as employment and livelihoods, as well as what they want to change to have their needs met, rather than considering what rights they thought they should have, and how to claim their rights. While this may reflect their historical exclusion from rights-based discourse, it reveals a challenge of transnational disability rights movements in engaging with the socio-political and epistemological foundations upon which social relations in the global South are framed. This requires us to decolonize the Western framing of human rights that, when applied to specific contexts in the Global South, usually fail to engage with Southern epistemologies and praxis (de Sousa Santos, 2014).

To tackle the tensions between a rights-based and decolonial approach, we engaged with the local knowledge on inclusion and exclusion as a way of re-framing rights from the participants' everyday experiences and create participatory spaces for the participants to claim their rights. Between 2017 and 2019, the research team conducted 3 participatory fieldwork visits with the girls and women in each of these communities. We also supported our local teams, including the DPOs, in the organization of 3 additional local workshops in Year 2 and Year 3 to build relationships with the girls and women and to ensure that the participants could strengthen their networks. The first stage (2016–17) included a five-day training workshop with women with disabilities along with a two-day participatory workshop with the girls with disabilities in each community. The second stage (2017–18) began with in-depth interviews and media analysis, followed by a four-day workshop with the use of photovoice, community-asset mapping, and reflections on their narratives. We also worked with a group of local film-makers and all the girls and women to create a documentary film, *Our Journey* (TDKRA, 2019). The film highlighted the voices and participatory engagement of the women and girls, as well as DPOs, in TDKRA. The final stage (2018–19) focused on community engagement activities, public film screening in the transnational, national, and local spaces, and re-imaging their leadership as part of their activist agendas.

In total, we worked with 54 girls and 31 women with disabilities. Criteria for inclusion and exclusion of the girls include: (a) aged 10–18 years old; (b) having experienced some forms of discrimination in and by the educational system; (c) having one or more disadvantages associated with their disability, class, gender, and ethnicity; and (d) experience of barriers to education and community. The DPOs used the recruitment procedures and criteria to recruit participants in their local communities. At the same time, we draw on the DPO's recommendations for recruiting participants in their communities. We also sought to ensure that our research is relevant to and respectful of the local practices. We did not restrict the age level of the women with disabilities.

The fieldwork included both training and data collection. Under the support of the trained women, the girls produced drawings, photos, and cellphilms, as well as engaged with their community members through an exhibition that displayed their arts and cellphilms. Here, we draw on data produced from photovoice and drawings to reflect perspectives of girls and women with disabilities about inclusion and exclusion, as well as their activism for their rights to inclusion.

The Process

We used drawings and photovoice to engage the participants in "picturing" their perspectives on inclusion and exclusion and to express their view of change. The drawings served as a way of engaging in conversation with the girls, especially with those who have language barriers. In a drawing workshop, participants were invited to think about issues such as "What is it like to be a girl with disabilities?" or "Girls with disabilities and the community." Participants used their drawings to tell stories about their space of living, schools, and communities. For the photovoice project, we used a number of prompts such as "Inclusion and exclusion," "Disability and diversity," and "Participation." The participants worked in groups of 3–4 girls. In each group, women with disabilities worked with the girls to support their engagement. The women were trained with basic steps in participatory visual methods. Each group took 6 pictures on inclusion and exclusion. They worked together to discuss their topics, including what they would photograph and how they would do it. One girl was assigned the role of camera person while the others staged the scenes. The women facilitated the participatory process by, for example, helping the girls to position the cameras or providing them with suggestions for how to enact their scenes.

The participants created their art productions in each fieldwork site. Interview data were collected in the second year. We triangulated our fieldnotes and observations, along with interview data and visual artefacts such as drawings and photos, in order to make sense of the participants' stories. Our methodology does not mean to verify the truth of their stories, but rather, to understand how participants used participatory visual methods as a way of empowering themselves to shape their narratives.

This collaborative process enhanced the engagement of the girls and women with disabilities. For example, in one case, we saw a woman supporting a girl with a visual impairment to take a photo by describing to her the landscape through their camera. This enabled the girl to imagine her photo through her blindness. We used cellphones with accessibility functions in Vietnamese to make this work more accessible to visually impaired participants. Some participants prefer using traditional cameras as accessibility functions designed by cellphone producers are not always easy to operate.

The participants were then asked to create what Mitchell (2011) refers to as a poster-narrative using the photos they took. The main purpose of creating a group narrative is to create a space of engagement where the girls would work together to develop their narratives. The participants were encouraged to be creative by using whatever forms or materials were available to represent their ideas (see Image 3 & 4) A caption was written to convey the girls' stories to the audience. In case language was not accessible to the girls due to their use of ethnic minority languages, the girls were invited to explain in their own languages. Two interpreters were hired to translate ethnic minority languages to Vietnamese and English.

In the drawing workshop, we engaged the girls and women with disabilities in each community in conversations about their homes, families, communities, schools, and friends. We used drawing as a method of seeing and understanding the participants' concerns and developing a reflexive and dialogical approach through their engagement. Our primary focus was not on the technical issues, but rather, on cultivating participants' thoughts and reflections through their arts. This approach was highly accessible for girls with different impairments. In the case of girls with visual impairments, a woman or peer worked with them to draw what they described or holding their hand to work together.

In what follows, we illustrate the outcomes of this participatory process through a number of individual and group products which were produced by the girls.

Findings

Representations of Inclusion and Exclusion Through PVM

Participants expressed their experiences with inclusion and exclusion through a variety of visual methods. Their experiences are vividly expressed through the visuals; through the drawings, images, colors, and captions, reflecting what might be most closely associated to their daily lives. For example, in her drawing, Vành Khuyên used bright colors to sketch her experience with schooling (Fig. 1). Located in the middle of the drawing is a one storey-house, which appears to be her school. Some girls are waving their hands to the right side of the drawing. To the left side of

Fig. 1 Drawing created by Vành Khuyên, aged 12, in response to the prompt: What's it like to be a girl with disabilities? Hanoi, 2017

the drawing is a tree with clouds and the sun rising on top of the drawing. Her caption reads: “Friends, please play with me!”

As a girl with intellectual disabilities, Vành Khuyên did not always find it easy to express things in verbal language. She remained largely silent during her interview due to the inaccessibility of verbal language. Thus, if the project had relied only upon interviews and focus groups, we would not have been able to learn about Vành Khuyên’s experiences and feelings about school. She was offered an alternative way to express herself through PVM and she actively participated. Interestingly, while the drawing seems to convey a hopeful message about her schooling through bright and colorful images, her caption suggests that the girl in her drawing is feeling quite lonely in school. Through the interview, we did learn that Vành Khuyên was usually teased and hit by friends. When asked why she was hit, she believed it was because of her disability. What may be inferred through her picture, then, is that although she loves being in school, she did not always enjoy her right to play and be included due to being excluded by her peers. The drawing, at the same time, expressed her desire to participate in the social aspect of schooling and to belong here.

Clearly then, despite a desire to belong in school, marginalization is a common issue expressed by the girls through their drawings (Fig. 2). This culture of exclusion is also reflected through Hạnh Phúc’s drawing:

Fig. 2 Drawing created by Hạnh Phúc, aged 15, in response to the prompt: What’s it like to be a girl with disabilities? Hanoi, 2017

As a girl self-identified as having intellectual disabilities, Hạnh Phúc was a Grade 8 student in a neighborhood school in her community. Her family is described as "normal" meaning that they are a working-class family. In her interview, she said that studying is "hard" but she enjoyed learning civic education and technology, and playing badminton in school. The picture shows three girls skipping rope while the girl to the left was marginalized from playing. Her conversation with the facilitator about the drawing reflects her experience with disability and gender-based violence in school:

Facilitator:	What do you want to say through your drawing?
Hạnh Phúc:	I want to be included with other children.
Facilitator:	Hạnh Phúc, is there anyone who teases you? How did they tease you?
Hạnh Phúc:	They spoke ill about my family.

In her interview, Hạnh Phúc also revealed being bullied by a boy in her class: "He scolds my grandparents and my parents." When asked how she felt about being bullied, she said she felt "sad" because "they do not respect me." Interestingly, while both Hạnh and Vành Khuyên reveal similar experiences with marginalization from play, the triangulation between visual and interview data reveals a challenging narrative of girls with intellectual disabilities: the extent to which these girls encountered disability and gender-based violence was significant and this requires action to be taken to tackle these forms of violence in schools (see also Nguyen et al., 2015).

The girls went beyond telling their individual experience to shape their collective stories using creative arts-based methods. For example, one group in Hanoi created a piece of art that represent their feeling of being discriminated against. The group used dry leaves in the school where we held the workshop along with colored pencils and the photos they took as the main materials for their art (Fig. 3).

In this poster, the group created two contrasting sections: the one with bright colors represents the feeling of inclusion and one in dark grey colors represents the feeling of exclusion. There were diverse representations of a girl with Down Syndrome and a Deaf girl in the photos. In her presentation about this art, Phuong, a group member described her group's photo narrative:

> This side (to the left), it is dark color, and in this side, light color. In this side [to the right], it shows that girls with disabilities are not included with others. The dark clouds stand for kind of being discriminated against. And the rain drops stand for our tears. And the withered leaves and trees are our sadness.

This art demonstrates the girls' creativity and imaginative visions on what inclusion and exclusion looks like using arts to express their feeling. The art was produced through their collective work where each girl demonstrated that they had a role in the creation of this project. Another group in A Luoi created their photo narratives by presenting the cultural activities in their communities such as singing, using a flute made with leaves, flowers and trees in their communities (Fig. 4).

Fig. 3 A poster-narrative as part of a photovoice project created by girls with disabilities in Bac Tu Liem, Hanoi, 2018

Fig. 4 A poster narrative as part of a photovoice project created by girls with disabilities in A Luoi district, Thua Thien Hue Province, 2018

This poster narrative, created by a group of ethnic minority girls and women in A Luoi district, is quite distinct from the previous narratives because it does not reflect their suffering experiences with human rights violations. Rather, they focus their collective efforts in community building by envisioning different types of cultural and social activities that they see themselves as capable of contributing to their communities. For example, in the middle of the poster is the self-representation of a woman with disabilities playing a leaf-made flute – a musical instrument traditionally produced by ethnic minority groups in Vietnam. She said that her grandfather taught her how to use this instrument since her childhood, and yet, this cultural activity was generally disappearing in her community as she grew up. The woman expresses her desire to sustain this cultural life through the caption: "blowing flute – Women and girls with disabilities contribute to demonstrating and maintaining the national identity of Ta Oi's peoples."[1]

The participants demonstrated their engagement in art-making as a way of re-imaging their individual and collective stories (see also Nguyen et al., 2015). A girl with disabilities responded to the question we raised in a local workshop: "How can the community listen to the voices of girls and women with disabilities?" by proposing strategies for mobilizing their knowledge and creating opportunities for their participation:

> I would like to respond [that] using media and sharing [it] in online community in order for other people to know our feelings, our desires for equality, inclusion, and development of people with disabilities in general, and girls and women with disabilities in particular. Bring pictures and videos to family and friends to have better understanding of their children in particular and the disabled community in general. When having an opportunity, we will show our works at the seminar, program related to people with disabilities (Be Mit, Knowledge mobilization workshop, Hanoi, 2019).

We argue that the strength of PVM lies in its arts-based, community-engaged, and decolonial approach to disability studies. By bringing communities together to share their collective experiences and responses, the girls make their voices heard loudly and clearly.

Discussion

As a party to the United Nations Convention on the Rights of Persons with Disabilities, the Vietnamese government has taken steps in implementing the CRPD into its domestic laws and policies (e.g., Socialist Republic of Vietnam, 2010, 2012). The institutionalization of the Vietnamese Law on Persons with Disabilities and related policies show that although the government has sought to

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[1] Ta Oi is an ethnic group located in the central province of Thua Thien Hue Province. The Ta Oi group share the border between Vietnam and Laos across the mountainous area of the Annamite Mountain Chain (Schmutz, 2013).

implement some aspects of the CRPD into law, Vietnamese social policy has maintained its biomedical and welfarist regime based on categories and levels of impairment, which defines who is eligible for social support (UNDP, 2020). The narrow application of anti-discrimination laws, along with the lack of access to substantive rights such as education, health care, social protection and services, and access to justice, have continued to hamper the progress of rights-based legislations in Vietnamese social policy.

However, as Meekosha and Soldatic (2011) argue, the CRPD's failure to address the global production of impairment in colonial and imperialist contexts has been a major drawback of this international convention. The transnational justice approach implicated in the CRPD ultimately rests on nation-states' interpretation and implementation of rights, thus failing to recognize that the state is both the granter and violator of human rights. Reflecting on the possibilities for participatory engagement with women and girls with disabilities in Vietnam, Stienstra and Nguyen (2020) contend that in order for disabled women and girls in Vietnam to claim their rights, researchers must engage with their voices, perspectives, and subjectivities because they challenge us to reframe, reposition, and ultimately, redebate the ways in which Western theories and frameworks may be ineffectively applied to particular social locations in the Global South.

As Stienstra and Nguyen (2020) argue, despite Vietnam's participation in various transnational frameworks such as the CRPD, Vietnamese cultures, histories and political structures have not been aligned with the deliberative democracy upon which the rights-based framework has rested upon. Post-colonial histories in Vietnam have been driven by different rehabilitative approaches in search for a cure of bodies who were impaired by its lingering wars with the French and United States imperialism (Nguyen, 2015). This necessarily sets a unique socio-historical context for thinking about the transnational dimensions of social justice and the global production of impairment which the CRPD has sidelined (see also Soldatic & Grech, 2014).

One important aspect of Participatory Visual Methodologies is the potential to create more inclusive and accessible spaces for engaging participants by empowering them to frame their stories from their own perspectives. This approach was particularly useful for decolonizing the Western framing of rights as abstract values and principles which, from our observations, have been less meaningful to participants. Instead, it enabled the participants to tell concrete stories about their inclusion and exclusion based on their ways of seeing. For example, while we asked the girls with intellectual disabilities about their experience being hit in schools, we usually got silences or inconsistent responses during their interviews. However, with the use of visual images produced by the girls themselves, they were able to recollect their memories based on their own ways of seeing and with minimal guiding questions by the facilitators. While we believe that the language of rights framed within the CRPD has been less useful for the participants in these communities, the use of PVM enabled them to frame their rights to participation and inclusion (Pinto, 2011) in a more concrete, embodied, and culturally relevant approach which sets a stage for their grassroots activism.

Furthermore, the use of these methodologies enabled participants to tell their stories that otherwise would be difficult, if not impossible, to explain in words. Indeed, we found that most girls were much more engaged in the creative aspects of PVMs than other traditional methods such as focus groups and interviews. While these methodologies were not entirely accessible to all girls, especially those with visual and intellectual impairments, this approach creates participatory spaces for disabled girls who would otherwise be excluded from research. This work is important for disability rights because it creates a more transformative approach to social justice by unsettling the traditional boundary between research and activism (Nguyen et al., 2019).

Conclusion

In this chapter we frame the use of participatory visual methodologies in our fieldwork in Vietnam with girls and women with disabilities as a way to approach a critical dialogue about disability rights in transnational contexts. As we have highlighted, these approaches have been key to centering the perspectives of girls and women with disabilities, in spaces where they may have previously been excluded. They have also been key to developing strategies for reaching audiences such as parents and other community members and policy makers. For example, the participants engaged in public screening and photo exhibitions of their visual products that were located in their own communities. This ensures that they not only participated but also mobilized their own knowledges. A key approach of our decolonial knowledge mobilization approach has been to mobilize the knowledge *with* the girls and women, ensuring that the participants can take ownership of their productions and use them as a tool for political activism. These participatory and decolonial strategies mobilized their rights to participation and inclusion through the entire research process.

Disability Studies positions people with disabilities as experts on their own lives and as such emancipatory research has been embraced by researchers in this field (Kanter, 2011). Oliver (1997) describes three elements of an emancipatory research project on oppression of people with disabilities as reciprocity, gain and empowerment: asking what do the participants get out of the research, who gains from it and can it be empowering? In the TDKRA project, the women and girls have been invited into a space to tell their stories and to be given a platform to have their concerns heard. This benefits not only the women and girls who participated in the project, but also their communities and families. Empowerment, in this context, has been seen in ways in which the women and girls have been able to take ownership of the visual productions and in their decision to share these productions with their communities, families and policy makers. For women and girls with disabilities in the Global South to be empowered, however, there is a need to recognize their distinctive contexts as well as reciprocal relationships among these girls and women in claiming their collective voices. Through the use of participatory visual methodologies, the women and girls have been able to position themselves as valued knowledge producers and articulate their desires for change.

The results have been inspiring both in relation to "shifting the boundaries of knowledge" (Mitchell, 2015) and in addressing the idea of whose knowledge matters. At the same time, this work has been illuminating in relation to implications for further fieldwork and new conceptualizations of participatory spaces for these girls to reclaim their ways of seeing, challenging us to think more critically about what it means to do decolonial research with girls and young with disabilities across Southern spaces (see, for instance, the ENGAGE research project, n.d.). How, for example, do we conscientize the various audiences so that the girls and women with disabilities do not feel in any way tokenized? Or perhaps more generatively and less from within a protective and paternalistic framework, how do we make sure that there is a decolonial space for the participants to critique audience responses?

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Part VI

Intersectionality

Intersectionality: Introduction

30

Nirmala Erevelles and Marina Morrow

Contents

Abstract

Intersectionality has been taken up uncritically in contemporary scholarship via an additive model where disability is merely added to other categories of difference, with an emphasis on a limiting essentialized understanding of identity. In this introductory chapter, we carefully delineate our understanding of intersectionality as a conceptual framework before we apply this understanding to critical disability studies. Drawing on Kimberlé Crenshaw's classic essay, *Mapping the Margins: Intersectionality, Identity Politics and Violence against Women of Color*, we argue that deploying an intersectional framework foregrounds the epistemic erasure of disability by other discourses of social difference and the epistemic labor of disability when it is constitutive of other categories of difference. In the final section of this chapter we showcase contemporary scholarship on intersectionality and disability.

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Introduction

Critical analyses of disability as a historical, social, political, cultural, and materialist category of difference eschew simplistic binary understandings of disabilities as either biomedical phenomenon or social construction. Instead, a critical disability studies approach focuses on the complex network of ableist structures that constrict/exclude/oppress disabled bodies/minds forced to exist within oppressive normative society. For disability studies to maintain its critical edge, the analytical tool of intersectionality is a crucial intervention precisely because of its assertion that systemic and structural oppression can only be understood through an interrogation of the complex, intersecting, and overlapping ways in which power operates via the social axes of difference, namely, race, class, gender, disability, age, sexuality, ethnicity, and nationality, mediated by the exploitative and oppressive workings of settler colonialism and transnational capitalism.

Intersectionality, however, has been sometimes taken up uncritically in contemporary scholarship via an additive model where disability is merely added to other categories of difference, with an emphasis on a limiting essentialized understanding of identity. In this introductory chapter, we therefore, want to carefully delineate our understanding of intersectionality as a conceptual framework before we can apply this understanding to critical disability studies. It is for this reason that we revisit one of Kimberlé Crenshaw's (1991) classic essays, *Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color*, to foreground the often-ignored key interventions Crenshaw makes to expose the epistemic erasure of Black women in legal discourses addressing violence against women. Utilizing similar maneuvers from Crenshaw's essay, we then describe how deploying an intersectional framework within critical disability studies not only foregrounds the epistemic erasure of disability by other discourses of social difference but also maps out the epistemic labor that disability is called to do when it is constitutive of other categories of difference (Erevelles, 2011, 2022). We argue that this intersectional recognition of both the epistemic erasure and the epistemic labor of disability offers a more nuanced understanding of both intersectionality and critical disability studies.

The final section of this introduction will then showcase contemporary scholarship included in this section on theory, activism, and lived experience that is committed to the process of examining and revealing the multiple and complex ways in which power operates to disenfranchise people with disabilities living at the intersections of difference within both settler colonialism and transnational capitalism. Contributors locate their work broadly in critical disability studies and disability justice and engage with intersectionality as both a theoretical framework and activist strategy within the domains of lived experience, policy, and activism. Each of the contributors pushes the boundaries of how to interpret, engage, critique, and survive the oppressive structures of ableist racialized heteropatriarchy, including offering constructive (re)imaginings of alternative frameworks of being and becoming that are committed to disability justice articulated and lived by grassroots communities of disabled activists embodying intersectional praxis. The chapters in this section also identify how power relations operate transnationally to reify settler colonial and capitalist practices and, in an act of refusal, propose anti-capitalist and decolonizing practices that are rooted in Indigenous knowledges and disability justice. Showcased here are the works of both senior and junior scholars/activists who bring their diverse perspectives based on their geographic location (global south and north) and social positioning via the axes of gender, race, class, ability, age, and sexual orientation resulting in a much-needed transgenerational conversation on ableism, intersectional embodiment, mad studies, the carceral state, and disability justice.

Intersectionality's Intellectual Roots and Theoretical Framings

Intersectionality is a conceptual theory that traces its intellectual roots to the activist work of Black women, Indigenous women, and women from the global south during the second wave of feminism (Combahee River Collective, 1977; Hill-Collins, 1986; Anzaldua, 1990; Lorde, 1984; Davis, 1981; hooks, 1984; Mohanty, 1984; Disabled Women's Network, 1988; Jamieson, 1979; Two-Axe Early, 1994; O'Sullivan, 2016; Hill-Collins & Bilge, 2016). Critiquing naïve notions promulgated by white women of shared "sisterhood" based on gender, these scholars/activists sought to highlight the ways in which women's experiences were shaped by racism, colonialism, imperialism, heteropatriarchy, ableism, and exploitative class relations. The term *intersectionality* was coined somewhat later by critical race theorist and Black feminist legal scholar Kimberlé Crenshaw (1989, 1991) to address the experiences of Black women/women of color/immigrant women in the context of domestic and sexual violence and anti-discrimination law. The impetus for Crenshaw's conceptualization of intersectionality was to expose how the violence that Black women/ women of color/immigrant women have historically experienced within intersecting communities and social structures is rendered invisible in both law and social policy. Crenshaw insisted that though violence against women is a universal and an oppressive possibility for most women, the actual experience of and social response to this violence are mediated by where women are located within social contexts structured by race, class, gender, sexuality, ethnicity, and immigrant status. Thus, for example, Crenshaw described how the legal system conceived of Black women as protected only to the extent that their experiences reflected those of either Black (men) or (white) women, not recognizing that their discrimination occurred at a unique confluence of multiple structures of oppression and identifications with multiple communities.

Crenshaw described *structural intersectionality* as the "intersectional subordination [experienced when] . . .the consequence of the imposition of one burden. . .interacts with preexisting vulnerabilities to create yet another dimension of disempowerment" (1991, p. 1249). Thus, for example, Crenshaw pointed out that shelters serving poor women of color/immigrant women fleeing domestic violence not only needed to provide temporary shelter but also had to contend with "other multilayered and routinized forms of domination" arising out of these women's cumulative experiences of gender and class oppression such as poverty, lack of childcare, few job skills for well-paying jobs, and/or their immigrant status. By failing to consider the intersecting structures that render these women vulnerable to multiple exigencies, all attempts to enable their empowerment remained inadequate.

Along with structural intersectionality, Crenshaw identified *political intersectionality* as another means of explaining why multiply marginalized women get short shrift. In this context, Black women get caught between the competing political agendas of antiracism and feminism, and because a non-intersectional politics evokes only one axis of subordination, these competing agendas cancel each other out leaving Black women vulnerable at these intersections. This is because, Crenshaw explains, without considering political intersectionality, anti-rape and antiracist agendas are "incapable of developing. . .solutions to the compound marginalization of Black women victims, who, yet again, fall into the void between concerns about women's issues and concerns about racism" (p. 1282). On the one hand, even the most race-sensitive anti-rape policies have only attended to how Black men have often been stereotyped as dangerous aggressors of (white) women (e.g., the myth of the Black rapist) and, as a result, experience the full brutality of the carceral state. Here, the racism experienced by Black men is foregrounded, and so, Black women are often cautioned to act in solidarity with Black men in these contexts. On the other hand, when Black women have been victimized through rape and/or sexual assault, there has been a tendency to dismiss the cases brought by Black women as unfounded based on perceptions of poor Black women as "transient, uncooperative, untruthful or not credible as witnesses in court" (p. 1282). Furthermore, Black women are often reminded that bringing accusations against men in their community only reinforces the stereotyping of Black men as rapists and, as a result, are exhorted to not put their entire community at risk. As a result, the "race- and gender-based devaluation of Black women" is naturalized and rendered invisible (1281).

Crenshaw added *representational intersectionality* to her explication of intersectionality as a problematic repercussion of political intersectionality as the earlier discussion intimated. According to Crenshaw, the problem of representational intersectionality describes "how the production of images of women of color and the contestations over those images tend to ignore the intersectional interests of women of color" (p. 1283). Using as an example the obscenity prosecution of the rap group 2 Live Crew in Florida, Crenshaw described how the arguments pitting the misogyny in rap music lyrics against the racialized stereotyping and targeting of Black male rappers as proponents of sexual violence was dependent on Black women being admonished into silence and located outside the pale of discourse. Here, Black women were expected to uncritically rally around misogynistic politics, racial profiling, and heteropatriarchal values and were thereby compelled "to serve as vehicles for the achievement of a 'liberation' that function[ed] [problematically] to perpetuate their own subordination" (p. 1293).

We have taken time to carefully explicate Crenshaw's conceptualization of intersectionality because much of this discussion has relevance when disability is admitted into the fray with other historical/social/political categories of difference. In the lazier conceptualizations of intersectionality (Watermeyer & Swartz, 2022) that have been so ubiquitous in the last few years, what has sometimes been passed off as an intersectional analysis has been the add and stir approach where disability has been added to the other categories of difference in a hierarchized litany that, though inclusive, engages identity categories as wholly essentialized and monolithic in their appearance. In the past decade, many critiques of intersectionality have sought to portray it as an overused concept that is past its prime. Labelled the "intersectionality wars" (Nash, 2019), some of the "standard criticisms" of intersectionality have included arguments that describe intersectionality as dependent on an identitarian framework where identity is wholly focused on Black women and/or solely including issues of race and gender to the exclusion of other categories of difference (Carbado, 2013). Some of this critique rings true based on simplistic interpretations of intersectionality by scholars eager to cover all their bases in abeyance to citational formalities. Additionally, the neoliberal academy and other state institutions, eager to showcase their liberal commitments to multiple difference, have appropriated intersectionality as a tool to demonstrate a problematic endorsement of diversity which then serves to deflect critique of the consistent institutional violence of the state. Claiming a post-subject post-humanist framing, Jasbir Puar (2005), for example, offering similar critiques pointed out that intersectionality can no longer address the complexity of difference in contemporary times. Puar (2005) wrote:

> As there is no entity, no identity to queer, rather queerness coming forth at us from all directions, screaming its defiance, suggests to me a move from intersectionality to assemblage. The Deleuzian assemblage, as a series of dispersed but mutually implicated networks, draws together enunciation and dissolution, causality, and effect. As opposed to an intersectional model of identity, which presumes components—race, class, gender, sexuality, nation, age, religion—as separable analytics and can be thus disassembled, an assemblage is more attuned to interwoven forces that merge and dissipate time, space, and body against linearity, coherency, and permanency. Intersectionality demands the knowing, naming, and thus stabilizing of identity across space and time, generating narratives of progress that deny the fictive and performative of identification: you become an identity, yes, but also timelessness works to consolidate the fiction of a seamless stable identity in every space. (p. 127–128)

While Puar's critique hits the mark regarding how intersectionality has been deployed in neoliberal contexts, it is unclear how her utilization of assemblages as a substitute for intersectionality offers a more radical take on the complexity of addressing multiple axes of difference. Moreover, there appears to be a misreading of Crenshaw's argument that offers a more complex reading of subjectivity than much of the liberal scholarship that utilizes intersectionality indicates. As our discussion of Crenshaw's work demonstrates, intersectional analyses may not be reducible to essentialized identity categories nor to stable subject positions. Rather, Crenshaw and fellow proponents of intersectionality make clear that identity categories are not distinct but are instead "always permeated by other categories, fluid and changing, always in the process of creating and being created by dynamics of power… [emphasizing] what intersectionality does rather than what intersectionality is" (Cho et al., 2013, p. 795).

Based on Crenshaw's analyses, what intersectionality does is to foreground the processes (e.g., structural, political, and representational) by which feminist and antiracist discourses (in her specific example, but not limited to it) have impacted the epistemic erasure of Black women. The nuance in intersectional analyses has been acknowledged in later writing by Puar (2012) who now argues for "thinking through the intertwined relations of intersectionality and assemblage…[because] it can… [more] fully understand relations between discipline and control" (p. 63). Taking this discussion into account in the next section of this introduction, we will discuss how disability makes its disruptive entrance into intersectional frameworks to foreground both its *epistemic erasure* and its *epistemic labor* alongside other categories of difference. In this epistemic space, disability is not reducible via the additive model to an essentialized identitarian category of difference but, rather, serves as an epistemic intervention via intersectional theorizations of difference.

Critical Disability Studies and Epistemic Interventions via Intersectionality

Intersectionality and its deployment within disability studies coincide with the rise of critical approaches in understanding disability and more specifically through feminist theorizations of disability (Garland-Thomson, 2002; Wendell, 1989; Morris, 1993; Shildrick, 2009, 2012; Thomas, 1999; Erevelles, 2011; Silvers, 1995; Hall 2017; Goodley, 2013; Kim and Schalk, 2021; Schalk, 2018, 2021; Pickens 2019; Kittay et al. 2001, 2002; DAWN-RAFH 1988, 2013). Critical disability studies, in its turn, emerged as an interdisciplinary response to changing social and intellectual developments, including post-structural theory (Goodley, 2013; Shildrick, 2009, 2012). That is, prior to its emergence, the primary focus of disability studies had been on the development of a social model of disability and on the material needs and the material effects of ableism (e.g., Oliver, 1990, 2004; Barnes, 2012). Critical approaches arose in part to expand analysis from the social model and Marxist materialist approaches in disability studies (Goodley, 2013) to include more cultural approaches to disability that engaged alternative/radical disability embodiment (Mitchell & Snyder, 1997; Snyder & Mitchell, 2006; Garland Thompson, 1997; Siebers, 2008, 2010; Sandahl & Auslander, 2009; Davis 2002). These approaches to disability have drawn on various strands of critical theory – including feminist, decolonial, Marxist, human rights, antiracist, intersectional, queer, and post-structural theories (Shildrick, 2009, 2012; Sherry, 2004; Titchkosky, 2007; Tremain, 2006, 2017; McRuer, 2006; McRuer & Wilkerson, 2003; Garland-Thomson, 2005; Kittay, 2019; Silvers, 2009, Wendell, 1989; Schalk, 2018, 2021; Pickens, 2019; Piepzna-Samarasinha, 2018; Bailey & Mobley, 2019; Miles, 2019, Kafai, 2021, Wong, 2020, 2022). What these critical approaches have in common are their challenge of the categorization of disability as only a biomedical phenomenon or social construction; their focus on how embodiment and complex intersectionalities are lived; their use of disability as a creative cultural force; and their commitment to work for more just social arrangements where disabled people can access all the rights of citizenship and live free of discrimination and violence.

However, notwithstanding the progressive turn in critical disability studies that foregrounds conceptual continuities with other theorizations of social difference along the axes of race, class, gender, and sexuality, disability (as a social category of import) continues to languish at the fringes of intersectional theories of difference. This is because disability's disruptive potential does not support the lazy additive tendencies of uncritical intersectional theorizing, and as a result, an explicit attention to ableism and the political embodiment of disability has been neglected in intersectional activism and scholarship (Bailey & Mobley, 2019). Feminist disability studies scholars of color have described how even though white feminist disability scholars/activists had historically looked at the intersections of gender and disability, they often ignored the implications of class and race beyond superficial inclusive gestures (Erevelles, 2011; Bailey & Mobley, 2019, Schalk, 2021; Mingus, 2017; Kim and Schalk, 2021). Similarly, scholars of Black disability studies have pointed out that while disability has always been present implicitly in intersectional analyses in the work of Black feminists (e.g., Nash, 2019; Schalk, 2021; Bailey & Mobley, 2019; Pickens, 2019), the field has often failed to make explicit its intersectional analyses with disability (Erevelles, 2011; Kim and Schalk, 2021; Pickens, 2019). As a result, disability studies have often been criticized for its "Whiteness" (Bell, 2006), and feminists fighting ableism who are Black, Indigenous, and people of color have called out their colleagues for not including disability in their analyses (Bailey & Mobley, 2019; Moore, 2015, 2017).

In the United States, Chris Bell (2006) made explicit the occlusion of race in what he called "White Disability Studies" while at the same time demonstrating disability studies scholarship as tied to Whiteness by enacting the epistemic erasure of disabled people of color communities. Similar to how Crenshaw described the epistemic erasure of Black women, Bell pointed out that:

> Far from excluding people of color, White Disability Studies treats people of color as if they were white people; as if there are no critical exigencies involved in being people of color that might necessitate these individuals' understanding and negotiating disability in a different way from their white counterparts. (Bell, 2006, Note 1, p 282)
>
> [Additionally, the other misconception is] that the disabled community is a monolithic one, struggling against the same oppressors, striving for identical degrees of dignity, recognition, and cultural representation. Such a characterization is a limited one that does not consider or address the rich diversity within disability communities—racial and ethnic diversity, for example. (Bell, 2006, p. 276).

Here, Bell cautions against the additive model of disability, where disability is added to the equation of other categories of difference to offer a more nuanced and complex analysis that very rarely questions how disability functions not merely as a social category of difference but also as a materialist intervention into the constitution of social difference in the first place. Bell's critique of White Disability Studies' "tendency to whitewash disability history, ontology, and phenomenology" (p. 275) can thus be read as a clarion call for an intersectional analysis that marks the *epistemic erasure* of disabled subjectivities living within multiply marginalized communities.

At the same time, including disability (which in our analysis includes psychosocial disability/madness) alongside other categories of difference has historically been a troubled enterprise. This is because disability is not merely a social category of difference; it performs a problematic form of *epistemic labor* in that it is deployed to structure the other categories of difference as Other by marking their deviation from a fictionalized norm. While the social categorizations of race, class, gender, and sexuality are largely conceived of as social constructions, disability has historically been located within the medical model as the embodiment of pathological deviance thought to be manifested via recognizable physiological/cognitive/neurological/mental differences. Here, the difference associated with disability is deemed biological (rather than a social construction), and as a result, the social category of disability, now perceived as the "master trope of human disqualification" (Snyder & Mitchell, 2006, p. 127), serves to justify the most oppressive aspects contained in the social constructions of the other social categories of difference. These pathological discourses of disability are used to justify the oppressive binary cultural constructions of normal/pathological, autonomous/dependent, competent citizen/ward of the state, as well as exploitative social divisions of labor (Erevelles, 2011). Put simply, multiply marginalized communities therefore feel compelled to disassociate/isolate from disability to demonstrate that their constitutive differences are social constructions and therefore fictive.

In fact, Crenshaw (1989) in "*Demarginalizing the intersection of race and sex*" uses the analogy of basement to explicate her theorization of intersectionality in ways that are instructive to the argument of the epistemic erasure of disability in discourses of intersectionality. Crenshaw writes:

> . . .[I]magine a basement which contains all people who are disadvantaged on the basis of race, sex, class, sexual preference, age and/or *physical ability* [my emphasis]. These people are stacked-feet standing on shoulders-with those on the bottom being disadvantaged by the full array of factors, up to the very top, where the heads of all those disadvantaged by a singular factor brush up against the ceiling. Their ceiling is actually the floor above which only those who are *not* disadvantaged in any way reside. In efforts to correct some aspects of domination, those above the ceiling admit from the basement only those who can say that "but for" the ceiling, they too would be in the upper room. A hatch is developed through which those placed immediately below can crawl. Yet this hatch is generally available only to those who-due to the singularity of their burden and their otherwise privileged position relative to those below-are in the position to crawl through. Those who are multiply-burdened are generally left below unless they can somehow pull themselves into the groups that are permitted to squeeze through the hatch.
>
> As this analogy translates for Black women, the problem is that they can receive protection only to the extent that their experiences are recognizably similar to those whose experiences tend to be reflected in antidiscrimination doctrine. (p. 151–152)

We quoted this argument in full to recognize that though "physical disability" is mentioned in the quote, the material conditions that would enable disabled people to clamber up the hatch make it next to impossible to do so. Moreover, for the most part, those who are non-disabled will most likely utilize the shoulders of those at the bottom to climb out. As such, not recognizing the geography of the basement as inherently ableist marks not only the epistemic erasure but also the epistemic labor that disability does to secure the liberation of other multiply marginalized communities.

Thus, as just described, the material effects of these ableist (dis)associations result not just in epistemic erasure but also in the overt erasure of disability even within social practices that claim to be liberatory. In fact, the very conditions for inclusion of disabled people within mainstream as well as multiply marginalized communities insist on their social assimilation (via special education, rehabilitation, assistive technology, and/or psychiatric treatment), failure of which results in their removal (via segregation, institutionalization, incarceration) or their complete annihilation, (eugenics policies, abortion of disabled fetuses) (Erevelles & Minear, 2010; Erevelles 2011, 2014a, b). Here, disability is conceived of as negative pathology as per the medical model, and therefore, the emphasis is on cure rather than care. Claiming that these pathologized bodies are located outside the boundaries of humanness, the violence that is done to them is justified because they are seen as the state of exception existing within the zone of bare life (Agamben, 2005). This then triggers the deployment of a necropolitics that casually consigns such pathologized bodies to what Achilles Mbembe (2019) has described as "death worlds" and/or "slow death" (Berlant, 2007). In this context, the epistemic labor that disability is called to do situates it as "the boundary condition that resides just on the other side of hope. . .the condition one must escape rather than improve" (Ferguson, 1987, 63) or as a marker to what Mel Chen (2012) has described as the structuring of animate life or animacies.

Additionally, following on Cho, Crenshaw, and McCall's (2013) exhortation to focus on "what intersectionality does rather than what intersectionality is" (p. 795), drawing on a materialist feminist disability studies, Erevelles (2011, 2022) has argued that disability exceeds simplistic identitarian politics because it is not just a condition of "being" but of "becoming," where this "becoming" occurs in a historical materialist context where multiply marginalized bodies "become" disabled via an intersectional analysis at the locus of multiple difference (Erevelles 2011, 2022). It is for these reasons that Jampel (2018) has argued for theorizing disability as a process that includes the interaction between the *social construction* and the *social production* of disability. She writes:

> The process of disablement is the interaction between the *social construction* [our emphasis] and the social production of disability. By social construction, I mean the ways in which language and culture, such as social norms, shape ideas about what bodies and minds are 'normal' and the ways in which ideas about the normal lead to social conditions in which people are disabled by their environments. . . Societal and cultural constructions include built environments, educational opportunities and ideas about independence. By *social production*, I mean the ways in which historical processes, ranging from human reproduction and genetic variation to the development of industry, have led to the diversity of human bodies and minds: material differences. . . Socially produced material differences include the physical pain of aching joints following years of labor, the effects of radiation exposure on a

> growing fetus, the changes in brains exposed to different levels of lead and the emotional distress that results from prolonged poverty. . ..[Here] disablement [is viewed] as a simultaneously material and discursive process. (p. 3)

Most critically, disability here is not an apolitical construct, the embodiment of natural difference. Instead, here, disability is a historical materialist construct – its production occurring amidst what disaster specialists term “complex emergencies,” which include “mixtures of civil strife, famines, genocidal activities, epidemics, and large-scale displacement and movement of refugees” (Carrigan, 2010). Thus, Carrigan argues that:

> These experiences are centrally implicated in the production of disability, which in many post-colonial states is a constitutive feature of community life. Not only do physical and psychological disabilities proliferate in disaster zones, but people with disabilities also represent one of the highest risk categories in terms of vulnerability to disasters—a point that is especially true of economically under- privileged postcolonial states in which medical care and institutional support networks are often lacking. (255–256)

If scholars were to refuse the epistemic erasure of disability in intersectional analyses, then it is essential that critical scholarship on race, indigeneity, class, and queer theory also recognizes that the historical legacy of the actual act of colonizing an inhabited continent, slavery, indentured labor, Jim Crow laws, and the involuntary commitment of Indigenous people to boarding schools and reservations has produced physical and mental trauma that has persisted over multiple generations (Spillers, 1987; Smith, 2005; Erevelles, 2011). For example, Indigenous activists and scholars have taken up the concept of intersectionality in multiple ways but with a distinct focus on the impact of colonialism and with a historical understanding of how Indigenous communities understood multiple categories of gender (Monture-Angus, 1995; Clark, 2016; Hunt, 2013). It has also been observed that Indigenous communities, as a direct result of colonial settler violence, are more likely to have disabling conditions (Durst & Bluechardt, 2004; Durst et al., 2006). Clark (2016) in her work on Indigenous girls in Canada argues for a “red” intersectionality that

> “. . . provides the tools to theorize not only the past but the current forces of colonialism as found within reserve politics, lateral violence, and identity politics. Red intersectionality recognizes the importance of local and traditional tribal/nation teachings, and the intergenerational connection between the past and the present, while also recognizing the emergent diversity of Indigenous girlhood and the geographic movement off and on reserve, and the construction of Indigenous girls through the Indian Act” (pg. 51).

Additionally, scholars and activists of disability have approached colonialism from their unique geographic and political histories, often challenging the dominance of Anglo-centric disability studies and its claims to universality by taking on the power and politics of knowledge production itself (Meekosha & Shuttleworth, 2009). Grech and Soldatic (2016) argue that the omission of disability from (post)-colonial scholarship and the hegemony of the global north in disability studies have done much to undermine both fields of study and activism. In the first instance, the absence of disability in (post)-colonial scholarship " continues to limit theoretical engagements with other fields such as disability studies and sociology of the body, which could contribute much to developments in postcolonial theory" (Grech & Soldatic, 2016, p. 2), and in the second instance, disability studies, "As a field of inquiry grounded within the epistemologies of the global North, it has rarely engaged with the 'colonial' beyond the realm of descriptive metaphor" (p. 2).

In contemporary contexts, undocumented workers cross the US/Mexico border dodging vigilantes, enduring dehydration and other heat-related diseases, and risking rape and sexual molestation to end up as laborers in fruit and vegetable farms, cattle ranches, chicken factories, and formal/informal service work for the lowest wages, unsafe working conditions, and little to no medical care (Holmes, 2013). Toxic industrial and nuclear waste is dumped in rivers and/or buried underground in landfills in low-income rural areas where residents acquire illnesses and disabilities that persist intergenerationally (Spears, 2014). Lack of access to affordable healthy food in inner-city neighborhoods, high employment, run-down housing, high crime rates, and inadequate access to medical care have also led to the proliferation of preventable illnesses that result in disabilities (Erevelles, 2022; Kim & Schalk, 2021). And lest we forget, the everyday indignities of racial profiling, bullying, job discrimination, police brutality, homophobia in the school and in the workplace, domestic violence, and sexual abuse, among so many others, also contribute to mental and physical health conditions that can bring one into the disability community. Here, a historical materialist analysis refuses the epistemic erasure of disability produced at the intersection of anti-Blackness, class, settler colonialism, transnational capitalism, and anti-queer politics.

Disability studies scholar Kelly Fritsch (2015) drawing on Jasbir Puar's (2009, 2012, 2017) conceptualization of debility situates this discussion within the context of neoliberal biocapitalism where the Foucauldian conceptualization of biopolitics is linked to the Marxist critique of political economy such that "individual and collective subjectivities and citizenships [are] both shaped and conscripted by . . .[bio] technologies that concern 'life itself'" (78). The biotechnologies that Fritsch is referring to include not just the technologies that debilitate bodies as described earlier but also those that capacitate bodies via processes such as "genetic therapies, surgeries, supplements, prosthetic enhancements, and healthism" (p. 27). Speaking specifically in the settler colonial context of Palestine in relation to the state of Israel, Puar describes vividly how, on the one hand, the colonial state produces disabled bodies via technologies that claim the "right to maim" while, on the other hand, other technologies are deployed to develop capacities for bodies that can be brought into the neoliberal economy for the realization of profits. Puar's conceptual shift in nomenclature from disability to debility thus marks the shift from "regulative normality that cures or rehabilitates to ongoing biological control, [to] where bodies are to be capacitated beyond what is thought of as the able-body" (p. 26). Here, Puar blurs the distinctions between disabled subjectivities and non-disabled subjectivities urging an attentiveness to "the ways in which differential inclusion functions, . . . to who gets to have grievances, how neoliberal biocapitalism capitalizes on those grievances, and the ways in which disability activists and scholars are implicated in their (re)production" (Fritsch, 2015). In these arguments, disability is not considered a predominantly oppressed identity category or form of embodiment of lacks or abnormality. Rather, we examine what it means for disability to be caught up in processes of both debility and capacity. Karen Soldatic (2011) in her work on neoliberal workfare restructuring in Canada, the United States, and the United Kingdom examines this tension and illustrates how it has resulted in new classes of disability – from the “really” disabled to the “just disabled” – and shows how social policy access flows from this: that is, who is “deserving” of welfare and who is designated to work in precarious labor markets. Such arguments thus also demonstrate the epistemic labor that disability is called to do at the intersections.

Crippin’ Structural, Political, and Representational Intersectionality

Having made the case for the epistemic erasure of disability even while appropriating disability’s epistemic labor, in this section, we work through how the three central elements of intersectionality – the structural, the political, and the representational – play out from the standpoint of disability. Bell’s critique of White Disability Studies articulated earlier maps out the analytical importance of structural intersectionality, where Bell’s insistence on the simultaneous recognition of ableist and racist structures can refuse the epistemic erasure of disabled people of color living in multiply marginalized communities. A good example of the deployment of structural intersectionality from a critical disability studies location has been the conceptualization of DisCrit (disability studies and critical race theory) as described by Subini Annamma, David Connor, and Beth Ferri (2013) in the specific context of education. According to Annamma et al.:

> A DisCrit theory in education is a framework that theorizes about the ways in which race, racism, dis/ability and ableism are built into the interactions, procedures, discourses, and institutions of education, which affect students of color with dis/abilities qualitatively differently than white students with dis/abilities (7)....DisCrit seeks to understand ways that macrolevel issues of racism and ableism, among other structural discriminatory processes, are enacted in the day-to-day lives of students of color with dis/abilities. (8)

A focus on structural intersectionality renders visible how students of color experience epistemic violence in educational contexts. Shifting from colonial practices to carceral education, in seemingly liberal spaces like public schools in the United States, low-income students of color are indiscriminately labeled behaviorally disabled, language disabled, mildly mentally retarded [sic], and emotionally disturbed and are then confined to segregated special education classrooms/alternative schools/juvenile detention centers; often medicated; and punished more harshly than their white counterparts (Artiles et al. 2010; Annamma, 2017). Within the United States and Canada where free public education shapes the social futures of every child and which has been (and continues to be) the battlefield on which issues of social justice via educational segregation, carceral practices, and the constitution of “spoiled” identities (Goffman, 1963) are distributed, the occlusion of disability within structural analyses of schooling needs to be remedied. This occlusion is problematic since the very logic of public education depends on the epistemic labor of disability to fulfill its functional mandate of sorting students on the basis their capacity to demonstrate able-ness/sanity and eschew all other differences. And yet, notwithstanding (or perhaps because of) this epistemic labor, disability experiences epistemic erasure except for its problematic hypervisibility in segregated educational space. It is here then that conceptual articulation of DisCrit – the intersection of disability studies and critical race theory – becomes significant (Annamma et al., 2013). Educational research has demonstrated DisCrit focuses on ways that the forces of racism and ableism circulate interdependently, often in neutralized and invisible ways, to uphold notions of normalcy. DisCrit, therefore, values multidimensional identities and troubles singular notions of identity such as race or dis/ability or class or gender or sexuality and so on. Additionally, DisCrit emphasizes the social constructions of race and ability while at the same time recognizes the material and psychological impacts of being labeled as raced or dis/abled, which sets one outside of Western cultural norms. The authors argue that DisCrit privileges voices of marginalized populations, traditionally not acknowledged within research. DisCrit considers legal and historical aspects of dis/ability and race and how both have been used separately and together to deny the rights of some citizens. DisCrit recognizes whiteness and ability as property and that gains for people labeled with dis/abilities have largely been made as the result of interest convergence of White, middle-class citizens. DisCrit requires activism and supports all forms of resistance (p, 19).

When disability is included in an intersectional analysis, it exceeds representational politics to also perform epistemic labor in the constitution of other categories of difference. On the one hand, as per Crenshaw's articulation of structural intersectionality, ableism intersects with other oppressive intersecting structures to impact social policy as well as the lived experiences of multiply marginalized communities as a tool to structure social difference. In fact, as many disability studies scholars (McRuer, 2006; Kim & Schalk, 2021; Erevelles, 2011; Schalk, 2021; Pickens, 2019) have pointed out, disability serves as a mode of justifying the social oppression of other categories of difference. This recognition of disability within the context of structural intersectionality thus explains the vexed relation disability has with other categories of difference – in that disability becomes the category to avoid rather than with which to build an alliance. Here, disability as structure marks the distinctions between "valued" and "devalued" life. In fact, it is only through the epistemic erasure of disability that other categories of difference can make claims to their own freedom. And in doing so, they effect the erasure of Black, queer, Indigenous, poor, gendered disabled, and mad people since there is little space in the discourse for them.

Echoing Crenshaw's foregrounding of the intersecting structures that render women vulnerable to multiple exigencies, Kim and Schalk (2021) in their Crip of Color critique also identify how ableist violence operates alongside and through heteropatriarchy, capitalism, and white supremacy and thereby demonstrate how feminist-of-color disability studies explores "unexpected points of affinities that might build coalition across categories (137)." And yet coalition is resisted because as Bailey and Mobley (2019) point out, Black people cannot afford to be disabled when they are required to be "phantasmically abled" in a white supremacist society (Bailey & Mobley, 2019, p. 22), This is because as the work of Leroy Moore (2017) and the Harriet Tubman Collective (2017) among others have pointed out, white disability uses disability as metaphor in arguing for their continued oppression. For example, an oft-quoted phrase articulated by white disability rights activists goes something like this: Black people fought for the right to not sit at the back of the bus, but disabled people cannot even get on the bus. Following up on this logic, disability studies scholars have challenged dominant ideologies of impairment/disability as being inherently negative and in constant need for amelioration/cure/elimination. Fiona Kumari Campbell (2019) calls this "de-centering the ableist imaginary." Here, Campbell identifies ableism as a structural system of oppression analogous to structural racism and argues for an epistemological and ontological inquiry into the formation of naturalized understandings of what it means to be fully human. Thus, Campbell foregrounds the ableist assumptions that support the habitual association of disability with a diseased and deficient pathology.

Campbell, nevertheless, falls into the familiar habit of reading ableism as analogous to racism, rather than theorizing racism and ableism as constitutive of each other. One problem with the analogy is that there is the assumption that disabled subjectivities are not racialized and racialized subjectivities are not disabled. Using as an example McRuer's (2006) deployment of the concepts "critically queer" and "severely disabled" as analogous, Kaul (2013) points out that the analytic power of the analogy fails to account for how historical representations of homosexuality as disability connects with the material consequences of queer bodies being incarcerated as "perverts" as well as the contradictory politics of including "gender dysphoria" in the DSM V – an inclusion that simultaneously pathologizes trans identities even while this inclusion enables trans-persons gain access to appropriate medical care. This then makes political intersectionality attuned to the inclusion of disability in discourses pertaining to difference.

Moving on to discussions of *representational intersectionality*, on the other hand, within communities of color, it is impossible to claim disability pride when disabled people often become disabled because of the violence of structural intersectionality. So, then it becomes a difficult space to engage with disability pride in communities of color when state apparatuses – prisons, police, schools, and welfare systems – rarely support the most precarious classes of people and, in fact, regularly brutalize those who are poor, undocumented, Black, Brown, disabled, trans, and/or gender non-conforming. Such apparatuses often operate as instruments of mass disablement that disproportionately target Black and Brown populations. How then does one represent one's disability at the intersections of difference? Bailey and Mobley ask us to:

> imagine a Black life that is more than just survival and more than able-bodied utopia. What does liberation look like if disabled Black bodies are allowed in our futures? Would we be better able to hold Disability Studies accountable for its erasure of raced and gendered bodies? (Bailey & Mobley, 2019, 34)

Kim and Schalk (2021) respond via their queer feminist-of-color disability analysis that aims to:

> demonstrate how disability is in fact central to the gendered and sexual management of women and queers of color. Instead of centering state-sanctioned understandings of disability, a feminist-of-color disability studies would prioritize considerations of state violence attending to the intersection of disability politics with abolitionist and anticarceral frameworks. . ... Indeed, Mingus, Piepzna-Samarasinha, and others like Leroy Moore, Patty Berne, Eli Clare, Stacey Milbern, and Nomy Lamm have come to . . ..insist on a movement that decenters those who can gain access to rights through a legal-based framework. They call this new framework disability justice. Feminist-of-color disability studies aligns politically and intellectually with this approach, allowing disability justice activism to inform feminist-of-color disability studies scholarship. (p. 16)

Intersectionality and Policy

Feminist scholars working in the context of health equity and public policy have championed intersectionality as an analytic lens and theoretical tool for policy development and analysis (Hankivsky, 2012; Hankivsky & Zachary, 2019; Morrow, 2022). These scholars critiqued domestic and international gender-based analysis frameworks and gender mainstreaming for solely foregrounding gender in their analysis and thus obscuring the lives and experiences of women, men, and transgender people situated at the nexus of multiple social positions (Hankivsky, 2012, 2022; Bacchi & Eveline, 2010). In some jurisdictions in the global north (e.g., Canada), the state has made a commitment to the policy framework of GBA+ as an approach to policy development (https://women-gender-equality.canada.ca/en/gender-based-analysis-plus.html), and some local governments have more explicitly adopted intersectionality (e.g., the Ontario Human Rights Commission in Canada, 2001). GBA+ in this context followed the adoption of GBA policy frameworks in Canada in the early 2000s onward (CIHR, 2012, 2018; Pederson et al., 2003; Salmon et al., 2006) and is an attempt to account for diversity among women and men. However, as discussed earlier, some have argued that GBA+ falls into the trap of the additive model of intersectionality, as it has yet to fully embrace the theoretical richness of intersectionality and what it can offer to policy analysis (Hankivsky & Hunting, 2022). As Hankivsky and Hunting (2022) demonstrate, to date, the dominant approach to adopting intersectionality is to attempt to integrate it into already existing approaches to gender inequities, and this has resulted in a misuse and misunderstanding of intersectionality, where gender is always foregrounded over other forms of oppression (Hankivsky & Hunting, 2022). Further, observations have been made about the uptake of GBA and gender mainstreaming and doubts cast as to whether it has resulted in any kind of transformative change (Hankivsky & Hunting, 2022). Emerging in this context has been the development of Intersectional Based Policy Analysis (IBPA) (Hankivsky, 2012). IBPA draws on the work of Bacchi's (2012, 2016) *What's the Problem Represented to Be?* (WPR) methodology which is informed by the post-structural practice of "problematization," that is, that social problems are not knowable to policy makers outside of their social embeddedness in practices of language and representation – or in other words, that social problems are not found but made. IBPA builds on this methodology but amplifies the social justice aims of the "problematizing" method by proceeding from a set of normative values and by introducing reflexivity (a key tenant of intersectionality) into the methodology itself (Hankivsky, 2012). Applying IBPA can help to surface the underlying values and assumptions that underpin policies and policy decisions and can also explicate the workings of power as it is manifest in state practices related to mental health and madness (e.g., Joseph & Morrow, forthcoming; Josewski et al., forthcoming).

Historically, international human rights approaches also relied on "gender-first" or "single-axis" approaches in enforcing legal provisions (Truscan & Bourke-Martignon, 2016). However, increasingly, there is a call to apply intersectional approaches in national and international human rights covenants. Researchers have highlighted that the UN Convention of the Rights of People with Disabilities (UN CRPD) puts forth intersectional approaches to policy and programming (e.g., Buettgen et al., 2018; Paré, 2019; see also UN Committee on the Rights of Persons with Disabilities, 2017, 2018). As such, increasingly, it is understood that the aims of the CRPD cannot be pursued without the use of intersectionality as an analytic lens that examines ableism in its intersections with sexism, poverty, racism, heterosexism, and gender-based discrimination (Buettgen et al., 2018; Bernasky et al., 2020; Bartlett, 2017; Judd et al., 2008) and colonization and indigeneity (Durst et al., 2006; Durst & Bluechardt, 2004; Fem Net North, 2016; Gillespie et al., 2016). While it is promising to see that intersectionality as a policy paradigm is beginning to take root, its use in the context of disability is still evolving, and much must be done to resist simplistic additive models (Buettgen et al., 2018; Bernasky et al., 2020).

Embodying Intersectional Analyses: Thinking Through the Chapters in This Part

> I imagine a world where our organizing and activism is less segregated, where our movements and communities are accessible and don't participate in the isolation of disabled communities. I imagine places where we fight for whole and connected people, families, and communities. Mia Mingus, *Leaving Evidence*

The five chapters that make up this section on disability and intersectionality are unique in their approach to intersectionality and disability justice. The authors take up the ways in which the experience of disability is intricately connected to systems of power based on racism, sexism, transphobia, transnational capitalism, and ongoing settler/colonial relations. Authors from the global south use intersectionality as a way to interrogate state systems of terror and torture in relation to how madness and sanity are socially organized (Kazemi & Karah); others in the global north (Shanouda & Langdon) use intersectionality as a tool to understand both oppression and resistance when they examine power as it manifests in nursing home care and the legal system. Hillier and Vostermans center indigeneity in their examination of how disability is taken up in relation to settler colonialism in the global north. Verlinden reads the trope of "monstrosity" through the lens of intersectionality to understand racialized, trans, disabled bodies. Wong, Deerinwater, Ho, and Thompson use conversation as a way of discussing the embodiment of intersectional social positions, how power operates in multiple overlapping ways, and the role that activism plays in continually challenging disability scholarship. Individually, each author makes a unique contribution to the scholarship of intersectionality and disability, and collectively, the chapters speak to our theme of the ways in which the epistemic erasure of disability by other discourses of social difference operates, but also maps out the epistemic labor that disability is called to do on the ground in real lives, in embodied activism and scholarship.

The first chapter is based on Erevelles and Morrow's two roundtable discussions with prominent disability justice scholar activists working in the context of the United States – Alice Wong, Jen Deerinwater, Sandy Ho, and Vilissa Thompson. Their piece entitled, "A Conversation on Disability Justice," grounds this section in the lived experiences of activism and the ways in which activists mobilize their own embodiment of multiple intersections of colonialism, sexism, racism, poverty, heterosexism, and ableism to undergird and inspire their social justice work. In their conversations, Wong, Deerinwater, Ho, and Thompson make visible the epistemic labor required to ensure that disability is not erased and that it is understood in a truly intersectional way. Much of their focus is on social activist movements (for Indigenous land and cultural rights, Black Lives Matter, queering disability activism, etc.) and the key importance of cross-movement learning and solidarity to achieve social justice. Among the many themes of our conversations were reminders of the power that the academy and especially scholars who embody social privileges have in defining what gets understood with respect to disability and therefore whose lives and experiences are foregrounded. Intersectional approaches demand a reflexivity that can unsettle power relations, and the conversations we had with Wong, Deerinwater, Ho, and Thompson stand as a reminder to academic disability scholars of the importance of grassroots activism involvement in theory development and strategies for change at the political level.

Chapter 2, "Mapping Intersections of Disability and Indigeneity," by Sean Hillier (a queer Mi'kmaw scholar from the Qalipu First Nation) and Jessica Vorstermans (a non-disabled White settler who grew up in an intentional community of people with and without intellectual disabilities just north of Toronto) takes the reader on a journey to understanding how indigeneity, disability, and disablement are experienced through shared processes of colonization in the settler states of Canada, Australia, New Zealand, and the United States through land removal and relocation to reserves, residential schools, violence, and the child welfare state. Their chapter begins with how disability was understood in Indigenous communities prior to European contact, and this knowledge is drawn on later in the chapter in discussions about reconciliation and healing. Hillier and Vorstermans center the dispossession of Indigenous land in the production of disablement and land reclamation by Indigenous peoples as key to disability justice.

In ► Chap. 33, “Madness as Response-Ability Against State Terror: A Case Study from Iranian Revolution,” Sona Kazemi and Hemachandran Karah, both racialized scholars situated in the global south, offer us an examination of the implications of state violence in post-revolutionary Iran. Through interviews with exiled political prisoners from the 1980s, they explore the ways in which madness and sanity are socially organized and imposed via state systems of torture and imprisonment. Kazemi and Karah note the resilience of their interview subjects and speculate as to how madness might be the “bodymind’s” response to the brutality of prisoner experience and a method of survival. Their transnational disability analysis “defetishizes” (Erevelles, 2011) disability, situating madness squarely within the social and political context of Iran.

In ► Chap. 34, “Monstrous Intersectionalities,” Jasper Verlinden explores the effects of the “sticky” web of signification (Ahmed, 2004) that “monstrosity” and the “monster” in their age-old representation of embodied difference have when understood intersectionally with attention to disabled, trans, and racialized bodies. Verlinden uses the case of Layleen Polanco, a Dominican trans woman who died in 2019 at the Rikers prison in New York, to highlight the material consequences of monstrous discourses for racialized, trans, and disabled bodies. Verlinden offers an intersectional analysis of monstrosity and the use of the monster itself as an intersectional analytic in order to “avoid either rendering the monstrous body into a mere sign without a referent or casting it as a dehumanized subject in need of rehabilitation” (Verlinden, this chapter).

In the final chapter of this section, “Black-Abundance, Fat-Revolt, and Crip-Desire: Intersectionality as Interference in the Life and Death of Rohan Garfield Salmon,” authors Fady Shanouda and Terri-Lynn Langdon honor the life of Rohan Garfield Salmon who died in 2019 after losing a prolonged legal battle with a senior living home and the corporation that ran it. Their chapter stands as an indictment of the nursing home industrial complex (Tremain, 2021) by grounding their analysis of Salmon’s experiences in the relationship between disability, race, and size. While highlighting the gross negligence and failures of the nursing home care system, their intersectional analysis also points to Salmon’s agency and resistance, which forestalled the state from exercising its force for several years. Ultimately, they argue that constricting forces from dominant understandings of fatness, Blackness, and disability can exist even as “fat/Black/disability becomings” (Shanouda & Langdon, this chapter) can act as forces that can disrupt the status quo and speak powerfully to oppressive forces.

Cross-References

- ► 2020 Pandemic and Refugees with Disabilities
- ► Decolonizing Disability: Indigenous Māori Perspectives of Disability Research in the Modern Era
- ► Disability and Aging: A Literature Review on Advocacy and Activism for Sustainable and Resilient Community Living

- ▶ Disability and Disaster Risk Preparedness
- ▶ Disability and Refugee Protection
- ▶ Disability, Conflict, and Environmental Conditions: Introduction
- ▶ Disability Paradigm Shifts: Models, Perspectives, and Philosophical Orientations Driving Change – Introduction
- ▶ Globalization and the Changing Face of Inclusive Development
- ▶ Madness as Response-Ability Against State Terror: A Case Study from Iranian Revolution
- ▶ New Politics of Disablement
- ▶ Rethinking Power and the Complexities Between Critical Disability Studies and Decoloniality in Higher Education
- ▶ Role of Culture and Legacy of Colonialism in Qualitative Research Methods with Persons with Disabilities in the Global South
- ▶ Studying Critical Disability: A Transformative and Inclusive Agenda for Social Change – Introduction
- ▶ Transhumanism and Disability
- ▶ Transnational History of Disability: Reflections
- ▶ Women and Girls with Disabilities in the Heart of the COVID-19 Crisis: Safeguarding Sex and Reproductive Health Rights
- ▶ Women Human Rights Defenders: A Case of Activism of Mothers of Children with Albinism in Tanzania

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A Conversation on Disability Justice and Intersectionality

31

Jen Deerinwater, Sandy Ho, Vilissa Thompson, Alice Wong,
Nirmala Erevelles, and Marina Morrow

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Abstract

Disability Justice as a concept and an activist practice was developed in 2005 by the Disability Justice Collective, a group that included disabled queers of color in the San Francisco Bay Area, Patty Berne, Mia Mingus, and Stacey Milbern, along with the founder of Krip-Hop Nation, Leroy F. Moore, Jr., and disabled trans activists Eli Clare and Sebastian Margaret (Kafai, 2021). Conscious of how the mainstream Disability Rights Movement and its academic arm, Disability Studies, had effectively erased the life experiences of poor, queer, trans, disabled communities of color, and instead centered the experiences of white disabled activists and scholars, the Disability Justice Collective was formed to counter this erasure. In her 2021 book, *Crip Kinship*, Shayda Kafai (2021) describes Disability Justice as "a movement building framework… [that] not only responds to gaps in the mainstream Disability Rights Movement but also offers principles framed in wholeness and persistence… to formulate strategies of survival for all our disabled queer of color bodyminds" (pp. 22–23). In 2015, Patti Berne, a co-founder of Sins Invalid, a grassroots arts activist organization, worked with disabled, queer, trans of colour communities, and fellow artist-activists to establish a written record of the key principles of disability justice that were published first in a blog post (www.sinsinvalid.org), and later in a manual entitled, *Skin, Tooth, Bone: The Basis of the Movement* (2019). The ten key principles of Disability Justice include: (i) a commitment to *intersectional frameworks*; (ii) relying on the *leadership* of those most impacted by disability justice; (iii) adhering to an *anti-capitalist politic*; (iv) a dedication to *cross-movement organization*; (v) and *cross-disability solidarity*; (vi) recognizing that *each person is full of history and experience and has worth* outside of the commodification of capitalist relationships; (vii) working towards the *sustainability* of on-going justice and liberation; (viii) meeting each other's individual and collective needs via *interdependence*; (ix) a dedication to *collective access* for brown, Black, and queer-bodied disabled people to be in community with each other; (x) and a commitment to *collective liberation* with no body/mind left behind (Skin, Tooth, Bones, 2019).

Disability Justice as a concept and an activist practice was developed in 2005 by the Disability Justice Collective, a group that included disabled queers of color in the San Francisco Bay Area, Patty Berne, Mia Mingus, and Stacey Milbern, along with the founder of Krip-Hop Nation, Leroy F. Moore, Jr., and disabled trans activists Eli Clare and Sebastian Margaret (Kafai, 2021). Conscious of how the mainstream Disability Rights Movement and its academic arm, Disability Studies, had effectively erased the life experiences of poor, queer, trans, disabled communities of color, and instead centered the experiences of white disabled activists and scholars, the Disability Justice Collective was formed to counter this erasure. In her 2021 book, *Crip Kinship*, Shayda Kafai (2021) describes Disability Justice as "a movement building framework… [that] not only responds to gaps in the mainstream Disability Rights Movement but also offers principles framed in wholeness and persistence… to formulate strategies of survival for all our disabled queer of color bodyminds" (pp. 22–23). In 2015, Patti Berne, a co-founder of Sins Invalid, a grassroots arts activist organization centered on queers of colour disability justice worked with disabled, queer, trans of color communities, and fellow artist-activists to establish a written record of the key principles of disability justice that were published first in a blog post (www.sinsinvalid.org), and later in a manual entitled, *Skin, Tooth, Bone: The Basis of the Movement* (2019). The ten key principles of Disability Justice include: (i) a commitment to *intersectional frameworks*; (ii) relying on the *leadership* of those most impacted by disability justice; (iii) adhering to an *anti-capitalist politic*; (iv) a dedication to *cross-movement organization*; (v) and *cross-disability solidarity*; (vi) recognizing that *each person is full of history and experience and has worth* outside of the commodification of capitalist relationships; (vii) working towards the *sustainability* of on-going justice and liberation; (viii) meeting each other's individual and collective needs via *interdependence*; (ix) a dedication to *collective access* for brown, Black, and queer-bodied disabled people to be in community with each other; (x) and a commitment to *collective liberation* with no body/mind left behind (Skin, Tooth, Bones, 2019).

From the above formulations, it is apparent then that Disability Justice frameworks understand ableism and the systems that sustain and support the oppression of disabled people as integrally connected to other forms of oppression as well as the social and systemic processes that prop up discriminatory practices and state violence. It, therefore, follows that Disability Justice centers the lives of people who experience intersecting forms of oppression based on race, citizenship status, gender identity, sexual orientation, age, gender, class, sanism, and the ongoing violent effects of colonialism (Piepzna-Samarasinha, 2018). Disability Justice activists have called for a conversation that moves beyond a sole focus on rights to better encompass the many overlapping and systemic forms of oppression that impact people with disabilities (Mchangama, 2015). As such, Disability Justice is a movement that is dedicated to transformative ways of thinking about oppression, one that sees the interconnections between fighting against police racist violence and the carceral state, environmental degradation and climate justice movements, the liberation of Black people, and the work towards decolonization and land repatriation for Indigenous peoples. It recognizes that the violence that is experienced by queers of color and transgendered people is intricately linked to the lives and experiences of people with disabilities. In other words, Disability Justice is, in fact, explicitly intersectional.

In 2021, we (Nirmala Erevelles[1] and Marina Morrow[2]) sat down on two separate occasions with four of the most renowned Disability Justice activists in the USA – Jen Deerinwater, Sandy Ho, Vilissa Thompson, and Alice Wong – to have a conversation about disability justice and intersectionality. Our conversations were wide-ranging and touched on themes related to disability activism, how disability is lived through the intersections of colonialism, sexism, racism, poverty, heterosexism, and ableism, and how the power relations that sustain oppression are being challenged and transformed. In our conversations, we also discussed the ways in which the disability activism that most often receives attention is that coming from disability scholars and activists who hold positions of relative power or who embody social privileges that allow their version of disability struggles to be heard over those of disabled people whose lives are marginalized through intersecting oppressions related to sexism, racism, sanism, and poverty, among others. These conversations, therefore, also include a critique of the role of the academy and privilege in shaping narratives about disability and the uses of the concept of intersectionality. What emerges from the insights shared are the ways in which intersectionality is embodied and how this has shaped each activist's intellectual and political contributions to disability justice. More importantly, each of these activists has foregrounded the key intersecting issues that shape Disability Justice politics and praxis, as well as their hopes and dreams for a future that will transform the ways in which we think about disability and intersectionality in a more socially just world.

The interviews were edited for readability and the flow of ideas.[3]

Introducing the Disability Justice Activists: Meet Alice Wong, Sandy Ho, Vilissa Thompson, and Jen Deerinwater.

We asked Alice, Sandy, Vilissa, and Jen to introduce themselves, highlight current projects, and tell us about their relationship to activism within the intersectional disability justice movement. We also supplemented what they said with information

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[1] Nirmala Erevelles is a Professor in the Social Foundations of Education and Instructional Department of Education Leadership, Policy, and Technology Studies at the University of Alabama. She publishes about various topics related to disability, in particular the ways social oppression is pervasive due to differences in race, socioeconomic status, and bodies.

[2] Marina Morrow is a Professor in the School of Health Policy and Management at York University. Her research uses critical mental health, Mad Studies, and intersectional frameworks to understand the social, political, and institutional processes through which health and mental health policies and practices are developed and how social and health inequities are sustained or attenuated for different populations. Marina strongly supports public scholarship and the work and activism of the Mad movement and Mad scholars.

[3] We would like to thank Abraham Joseph for his support in transcribing the interviews.

that we obtained from their websites and other Disability Justice Organizations that have benefitted from their leadership and insights.

Alice Wong is the director of the Disability Visibility Project – an online community whose central project is to design, create, share, and amplify disability media and culture. Wong is also a co-partner in three other projects: DisabledWriters.com, a resource to help editors connect with disabled writers and journalists, #CripTheVote, a nonpartisan online movement encouraging the political participation of disabled people with co-partners Andrew Pulrang and Gregg Beratan, and Access Is Love with co-partners Mia Mingus and Sandy Ho, a campaign that aims to help build a world where accessibility is understood as an act of love instead of a burden or an afterthought.

Wong has earned bachelor's degrees in English and Sociology from Indiana University at Indianapolis, and a master's degree in Medical Sociology from University of California, San Francisco.

Wong has made critical contributions in the areas of popular culture, media, politics, disability representation, Medicaid policies and programs, storytelling, social media, and activism. She has been published in the *New York Times*, KQED, Vox, Radiolab, PEN America, Catalyst, Syndicate Network, *Uncanny Magazine*, Curbed SF, Eater, Bitch Media, *Teen Vogue*, Transom, Making Contact Radio, and *Rooted in Rights*. Her activism and work has also been featured in the CNN original series *United Shades of America* (Season 3, Episode 4), *Huffington Post*, WNYC's *Death, Sex, and Money* podcast, KQED's *Truth Be Told* podcast, *Wired*, *The Hill*, Autostraddle, WNYC's *Werk It: The Podcast*, *The Guardian*, Roll Call, WBUR radio, Al Jazeera, *Teen Vogue*, Bitch Media, Rewire, Vice, *Esquire*, CNET, and Buzzfeed.

Wong has won many awards for her service and activism at the local and national level. She received the Beacon Award by the San Francisco Mayor's Disability Council in 2010 and the Disability Service Award by the University of California, San Francisco, in 2011. From 2013 to 2015, she served as a member of the National Council on Disability, an independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities. Wong is the recipient of the 2016 AAPD Paul G. Hearne Leadership Award, an award for emerging leaders with disabilities who exemplify leadership, advocacy, and dedication to the broader cross-disability community. In 2018, she was featured in the Bitch 50, a list recognizing the most impactful creators, artists, and activists in pop culture by *Bitch Media*, and in Colorline's 20 × 20, a group of transformative leaders reimagining what it means to advance racial justice. In 2020, she was named by *Time* magazine as one of 16 people fighting for equality in America. Along with 19 other disabled artists, Wong was named a Disability Futures fellow, a grant by the Ford Foundation and the Andrew W. Mellon Foundation administered by United States Artists. Wong also received the Indiana University Bicentennial Medal for her contributions to disability justice and broadening the reach of IU around the world. In 2021, she was named a changemaker by Marie Claire magazine, and in 2022, she was included in Gold

House's A100 List, a list honoring 100 Asians and Pacific Islanders who had the most impact on culture and society over the past year.

Alice Wong is the editor of *Disability Visibility: First-Person Stories from the Twenty-First Century* (2020), an anthology of essays by disabled people and *Disability Visibility: 17 First-Person Stories for Today*, an adapted version for young adults (2021). Her debut memoir, *Year of the Tiger: An Activist's Life*, is available now from Vintage Books. *Disability Intimacy*, her next anthology, will be out in 2024.

Sandy Ho is a community organizer, disability policy advocate, and resource mobilizer with a longstanding commitment to grassroots disability activism and advocacy. She is the founder of the Disability and Intersectionality Summit – a biennial national conference that uplifts and celebrates the lived experiences of disabled people of color. Most recently, she has been a disability policy researcher at the Community Living Policy Center at Brandeis University, where she coordinated disabled-led research to strengthen and improve practices to keep people with disabilities in the community. While working with Thrive, the Easterseals mentoring program, Ho created a program that matches young women with adult female mentors who have disabilities in order to help the mentees develop leadership skills, learn to advocate for themselves, and set goals for their future. Through its social media component, the Letters to Thrive project, Ho has asked the mentors and young women to write to their younger selves with words of advice or life lessons they have learned. This popular blog has now gained currency globally.

In 2021, Ho was a distinguished Longmore Lecturer with Ryan Easterly and Bridgit Antoinette Evans, and in 2015, she was recognized as a White House "Champion of Change." In 2022, she received a Disability Futures Fellowship supported by Ford Foundation and The Andrew W. Mellon Foundation. Currently, she is also the director of the Disability Inclusion Fund at Borealis Philanthropy. You can follow her on twitter @NotYourAvgHo101.

Sandy is completing her master's degree in Public Policy at the Heller School for Social Policy and Management. In summarizing her work, Ho says, "I think that my relationship to activism is making sure that we are having space for multiple marginalized disabled people to present on habits and their passion and joy and issues that are that are important to them, to better our community."

Vilissa Thompson is the Founder & CEO of Ramp Your Voice!, an organization focused on promoting self-advocacy and strengthening empowerment among disabled people, and a senior fellow at American Progress. Thompson has been consistently on the front lines of ensuring discussions of race and gender are inclusive of the experiences of disabled people on various issues. In 2016, she launched #DisabilityTooWhite, a hashtag that offered an important critique of media coverage, community leadership, and public policy that centered whiteness, as opposed to those who are most affected by the intersections of racism, sexism, homophobia, and ableism. This led to Thompson's construction of the groundbreaking Black Disabled Woman Syllabus with its focus on women's health, carceral reform, body positivity, and mental health. In recognition of her advocacy work, she appeared in *Essence* magazine's 2018 "Woke 100 Women." Thompson has also appeared on MTV, Healthline, The Hill, NY Times (2017/2020), Black Women Radicals, Huffington Post, Buzzfeed, Bitch Media, Upworthy, Daily Dot, Daily Beast, and The Atlantic. She acted as a consultant for Sen. Elizabeth Warren's 2020 Presidential campaign, where she assisted in the development of the Disability Rights & Equality policy plan.

Thompson received her B.A. in psychology and her Master's degree in social work from Winthrop University. She is a Licensed Master Social Worker (LMSW) from Winnsboro, SC. As a member of the National Association of Black Social Workers, Thompson continues to educate her peers in the social work field to look beyond the medical model of disability.

Thompson describes her activism as follows: "I am a social worker, activist writer, speaker and consultant, and I created my business Blog called Ramp Your Voice in 2013 as a way to bridge the identities that I have, both professionally and personally as a Black woman who's a social worker, and who lives a very intersectional experience that has influenced the way that I view the world and the way the world engages with me. Some of my body of work like... #disabilitytoowhite really brought forward the conversation about racism and exclusion... as well as really engaging intersectionality in a way that allows for conversation to be had in certain communities, particularly the Black community... Especially when it comes to how do we talk about the Black experience in its wholeness, in its fullness and not exclude disabled Black people... who have made tremendous contributions to the community. And I also talk about the racism and anti blackness within a community where we may not always feel welcome in that space due to ableism and sanism in that space. So I am really talking about how both communities can do better to be safe havens for Black people and what does that look like."

Jen Deerinwater is a bisexual, Two Spirit, multiply disabled, citizen of the Cherokee Nation of Oklahoma and an award-winning journalist and organizer who covers the myriad of issues hir communities face with an intersectional lens. Jen is the founding executive director of *Crushing Colonialism*, a non-profit Indigenous led multimedia organization, and a 2019 New Economies Reporting Project and a 2020 Disability Futures fellow.

Jen received a B.A. from the University of Southern California in Gender Studies and Political Science with an emphasis on American Federal Government, a Graduate Certificate in Women in Politics and Public Policy from the University of Massachusetts-Boston, and an M.S. in Communications Management from Simmons College.

Jen is a contributor to Truthout, and hir work has been featured in a wide range of independent publications, including Bitch, Rewire, News, In These Times, and New Now Next. Jen's writing is included in the anthologies Disability Visibility: First Person Stories from the Twenty First Century (2020), We Organize to Change Everything: Fighting for Abortion Access and Reproductive Justice (2022), Property Will Cost Us the Earth: Direct Action and the Future of the Global Climate Movement (2021), and the forthcoming Crip Authorship: Disability as Method

(2023). She's the co-editor of the anthology Sacred and Subversive (in process) and is currently hard at work.

Deerinwater describes her many activist roles as follows: "I'm a citizen of the Cherokee Nation of Oklahoma. I grew up between rural areas of my nation's reservation in Oklahoma and in Abilene, Texas. So, I've mostly been living in large cities, and... urban areas... since I left home for college, and I now live on occupied Piscataway land known as Washington DC. Let's see what else... so I'm also bi and two spirit, and I'm the founding executive director of 'Crushing Colonialism.' I am a freelance journalist, I'm a writer, a photographer. I do a little bit of the arts and media and then along with that, community organizing which I've been doing for 20 years now. I also feel like it's important to mention that I worked in politics, off and on, for about a decade. And, in particular, I worked a lot for the Democratic Party. I ran political campaigns, and I worked in... liberal advocacy organizations rather than justice-based organizations. And it was partially being in that world and doing that work that actually pushed me so far to the left... I am multiply disabled. I have chronic pain, I have some chronic illnesses, autoimmune issues. And I also have complex PTSD. I don't think of that though as so much as an illness, but rather [as a] perfectly rational response to traumatic experiences that should have never happened. But I feel like it's really important to say that because it is something that I struggle with partially because of who I am and the way the world treats people like me and the way that those identities and those oppressions just keep layering and piling on. In terms of Disability Justice, I didn't really start coming to it, until my 30s. You know, like for example I spent a lot of my 20s doing pro-choice work and the longer I was there, the more I went... nah... I think reproductive justice is what we need, you know, and that's kind of the direction I've shifted to with all my politics. But it really wasn't till my 30s that I got involved with Disability Justice. And I think there are a lot of reasons that I waited until my 30s. Up until my 30s I had mostly been able to kind of hide my disabilities. I think I struggled... between my own internalized ableism, and just the abuse and the discrimination that I encountered as a disabled person that I hid it for as long as I could."

Thinking with and Through Embodied Intersectionality

NE & MM: Can you give us narratives of how your lived experiences both as individuals and as activist communities embody intersectionality?

Alice Wong

My embodied experience is intersectional. I don't like to use the word to describe that lived experience because it just is, and I feel like this word, and this concept by Dr. Kimberle Crenshaw, and other Black feminist scholars and other sisters is so overused. It's been misappropriated, and it just... it rings hollow for a lot of people. It's just a buzzword now, and it's often misunderstood. And it's used oftentimes as a replacement for the word diversity. But it's not about diversity. And I find that troubling. I really find that disturbing as well because… it's not just my own experience, but it's about this larger system which has a space of oppression… which is different than our individual experiences. But the fact that people are asking. "What's it like to be an Asian-American and disabled and a woman?" How do I answer that? You know, I find those questions to be not helpful. And not useful, you know? And I feel like as a marginalized person that it kind of says more about the people that are asking these questions of a study, they are just reducing me down to these check boxes. You know, I think our experiences are very messy, very full of nuance. To separate experiences that are deeply intertwined, right? Ableism, racism, sexism, other forms of oppression. And you know, I just feel very tired at this point to be asked these kinds of questions. And I feel like it's a very kind of simplistic way of talking about diving deeper into intersectionality.

I think for me, where I'm at right now as a 40-something activist, I think I'm getting a little bit, you know, impatient and a little bit salty about this, and I think it's good to feel salty because so much of this work is white people's work, and in particular, white scholars, or white disabled scholars in disability studies, or any scholar in academia. The disability justice movement is inherently intersectional. So, we should just call it the intersectional disability justice movement. It just is. And this is another kind of education and understanding – that disability justice was forged primarily by disabled people of color.

Sandy Ho

I very much agree with what Alice was saying… the start of the response regarding the redundancy of that question around like… what is the relationship around intersectionality and disability. I think that the question also kind of presumes that we had a choice to begin with, which many, many more marginalized people of color, and women in our movement who are doing this work, who are doing not just the community activism but also making sure that we're taking care of one another. It is like, well, that's just how we live our lives… But, in terms of my activism and in terms of intersectionality, part of the reason for why my friends and I who are also disabled people of color started D.I.S., The Disability and Intersectionality Summit, was because we saw that a lot of, for instance, Ted Talks, and other presentations, and other conferences, were giving platforms, and microphones to white disabled people, … most of whom… were, coming from an upper socio-economic class … had obtained the credentials that made them acceptable to the Academy, or to other professional institutions and were framing disability around, and telling narratives around disability that just did not resonate with the community that I know… so we're like where's the… conferences and the places for us to tell our own story?… I think that when Kimberle Crenshaw established this framework, it was also about working for where power is most held. And so, it is then unsurprising that one of the principles of the Disability Justice framework is leadership by those most impacted… And so, I think, that intersectionality is not just like a guiding principle, but it's something that we really hold to align ourselves closely with.

Vilissa Thompson

My very existence is intersectional… I've always been aware of what it means to have multiple identities as a Black person from the south, dealing with racism – understanding the history of racism in our country and understanding the history of white supremacy in our country, understanding how Black people are impacted in general, and then breaking it down as a Black woman. It wasn't really until I began doing this work where disability shifted from being a medical understanding to a cultural identity. Now understanding that nuance is there. And also combining that as a Black disabled person… specifically as a Black sane woman. What do all these histories mean for my existence? What do all these histories mean for my understanding of self? In a lot of my work when I talk about intersectionality along with privilege and biases, I encounter a lot of white folks, both disabled and not disabled, who want to challenge me on privilege. And somebody asked me about my own privileges, and as a Black sane woman, I am fully aware of my privileges. Some of that is being a light-skinned Black woman that some consider racially ambiguous – even though I don't see that but when I go out in the world and I am asked… am I, anything other than Black, then it makes me know that oh, I do not just exist as a Black person, I exist in this othering of blackness because of my lighter complexion. Having educational privilege, being somebody with a master's degree… I know that those things allow me to get into a certain room and get certain connections easier than some other people of color. When I go out into the world (being here in South Carolina), some people don't care that I'm Black, but some people care that I'm in this wheelchair. People may not care that I'm in this wheelchair, but they care that I'm Black. But people may not care about that wheelchair or [about] me being Black, but they care about me being a woman. And some people care about all three. So, the embodiment of intersectionality is something that I don't really have to think about, it just… this is my life. In doing this work as an activist… one of the things that really struck me when I became more engrossed with the activism part of disability spaces, was the failure to understand how we all embody these identities in… different ways… But as Alice has said, and I think Sandy has, we know that this work (on teaching about intersectionality) is really for white folks… We're not the ones that need to be taught here. It's like the white sane folks and the white scholars… and white people in general, they need to be taught these things because they don't have to think about it…

Alice Wong

Just building on what Vilissa just said, which is so true. I spend a lot of my time on Twitter… I still see… white disabled people using the hashtag #disabledlivesmatter. Which is completely inappropriate. You know, cooptation of #blacklivesmatter… And I see this conversation again, and again and again… So why does a disabled person do this? "We're the most oppressed… Disabled people are always the last to be included, or disabled people have it worst or just disabled people are, you know, are always like forgotten." . . . And then disabled people of color will usually gently or firmly say, "Hey uh, you're definitely forgetting or erasing or harming disabled people of colour." . . . And then there's all this fragility and defensiveness. "You don't know how hard I've had it. . ." This is quite true that we don't want to say they haven't been through things. All of us have struggled. All of us have gone through difficult things. But that is often used as a defense for not listening to why disabled people of color have. . . different hardships. . . I see other issues where white disabled people try to really center themselves, but they should not be centering themselves. You know, I am talking about police brutality and the fight for Black lives or disabled Black and Brown disabled people and how Indigenous people should be at the center. . . And yet, white disabled people have very little problem thinking about themselves and thinking about their experiences with law enforcement or just all these other things.

Vilissa

And especially jarring, because I think with disabled people, centering ourselves is kind of what we do when it comes to our bodies and experiences. We have to be mindful. I know that for me I need to be aware, particularly somebody with brittle bones, how people lift me and how people pick me up and engage with me. . . So, in some ways, this self-centeredness is bred unconsciously because we always have to be aware of our bodies and our minds and [our] interactions. . . And this self-centeredness particularly with white disabled folks fail to look beyond. . . themselves because white people don't have to. Whiteness is the culture. Whiteness is the definition of everything. And white disabled people fail to see that when they talk about [their] disability issues, white experience is the standard. Their faces are the standard here. When we have these telethons, when we have representation in the media, it is [usually] white people. So, they are never going to be left out. In some ways, it's over saturated with whiteness and disability. . . And I think that's one of the most frustrating things is seeing white disabled folks try to do #disabledlivesmatter, or question the work that we do if we're looking just to highlight, disabled voices of color. Because white people are never going to be erased. They are always going to be considered important. Why can't you just allow space and room? And in some ways, pass the mic for those of us who never get heard, who are always invisible, who always have to fight to even get some type of crumb. . .?

Jen Deerinwater

. . . I knew that once I came out as disabled, I would never work in politics again. . . I felt like if I came out as disabled, I wouldn't be supported by the Democratic Party. I felt like voters wouldn't be interested in me, especially, you know, already being Native and bi, a woman, and all of these other things. So, I hid it for a very long time. And 1 day I just, I couldn't hide it anymore, and I didn't want to fight it anymore. It was like. . . physically, I couldn't hide it. And I just didn't want to anymore. . . Why did I have to hide something about myself and be ashamed of it, when I'm not the problem? The system is the problem. The Democratic Party is the problem. The Republican Party, you know, is [the problem]. . . So, I think, it was, a lot of that, that kind of pushed me in the direction of justice-based movements, but also kept me out of them for a while. I also just never really saw space for myself in a lot of movements, you know. Up until really. . . the #NODAPL (Dakota Access Pipeline Protests) at the Standing Rock Reservation, most non-Natives had no interest in working with Native people. They didn't care about Native issues. They didn't care, and I still think a lot of people don't care. . . . I didn't see myself in that way, you know, in the larger queer community as a bisexual and a two spirit. I didn't really see myself being welcome. . . I feel more comfortable in Disability Justice spaces but [in the] disability community, as a whole. . . I don't feel seen as a Native person. You know, so. . . that's also been a problem. It's not just the liberals or the moderates, or the right. It's our own communities, you know, doing that disconnect and, you know, sort of keeping our people apart.

. . . In the so-called United States (and I say so-called because this is not the United States, this is Indigenous land, whether it's recognized as such or not), when you look at who is the most likely to be disabled. You know it's Indigenous people. Native people have the highest rates per capita of disabilities in this country. We have horrible rates of chronic illnesses. And a lot of it is perfectly preventable. We are not genetically predisposed to diabetes. Diabetes really came up in our communities in the last 100 years or so, and a lot of that is because we were removed from our lands. Or our lands have been poisoned over the years. Or our food sources were taken from us through things like. . . the bison slaughter, for example, for our relatives out west, or the damning of rivers, which then stops the natural flow of salmon. Things like that have disconnected us from our foods in our traditional ways of life. And that's part of why we have such high rates of diabetes. We are disproportionately impoverished. We have higher rates of food insecurity and starvation. And so, I guess I also sometimes feel a little disconnected, in some disability spaces where people have this pride about being disabled. And I think that that's really amazing. But for me, when one is a chronic pain sufferer, it's hard to feel pride in a body that is attacking me and making my life so much more difficult. But how am I also supposed to feel pride when I'm looking around at illnesses and disabilities within my community that are absolutely a result of genocide, of colonization, of the climate crisis, and environmental degradation? You know, that's not something I feel pride in, and so I still sometimes feel kind of out of place in disability community and Disability Justice spaces, but I guess I feel like there's enough room for all of us and all our voices need to be heard, so I just keep trying to show up.

You know I don't always feel comfortable in all of my communities. I mean, oftentimes with Native community, I have to be like, "Hey, there are queer Natives. We exist, you know. There are disabled Natives. Can we talk about this?" I think another part of the disability and Indigeneity piece that I think is really important and something I'm still learning about is a lot of Indigenous cultures, nations, and communities didn't have words like disability. You know, "disability," "being deaf" – those things that could have been something completely different. You could have been seen differently. You could have been treated differently. You weren't necessarily going to be seen as a burden on the community, you know. So, I think that that's one important aspect to being disabled and Indigenous, but also at least within the so-called USA, there is also a long history of state governments coming in and saying that native people are disabled or ill or mad, when we're not. You know, if you look at the Hiawatha Insane Asylum for Indians, for example... that is part of that colonization piece, you know. It's a way of disconnecting us from our people. In the State of South Dakota, a lot of Native children get labeled as disabled because the state of South Dakota gets more money from the federal government if they have more disabled children. Prior to the passing of the Indian Child Welfare Act (ICWA) in 1978, studies found that 25–35% of all Native children were removed from their home by state child welfare and private adoption agencies. Of those, 85% were placed with non-Native families, even when good homes with relatives were available. In the State of South Dakota, for example, many of the Native children stolen from their tribes are labeled as disabled because the South Dakota government is given more money from the federal government if the children in foster care are labeled as disabled. The Supreme Court of the United States held a hearing on November 9, 2022, that could overturn ICWA, meaning not only could more Native children be stolen from their communities, but the entire right to exist as sovereign nations go away.

And so, a lot of Native children are in foster care, being stolen from our communities when there's absolutely no reason for them to be separated other than genocide. And then they'll label them disabled whether they are or not, so that they just keep getting money... So, I sometimes think some Native people are very afraid of being called disabled, and partially because of that... I think we're also a very insular community with very real trust issues. For very obvious reasons, we have trust issues. So, I think many of us are still in this place of constant fear of being murdered. And you don't want to expose your weaknesses, and if your enemy knows, oh hey like you've got x, y, and z health problems or disabilities, that can be used against you. So, I think sometimes we don't like to talk about it and own that as Indigenous people because we're still being killed, you know genocide hasn't ended for us.

Disability Justice: Key Issues

NE & MM: As activists in intersectional disability justice movements what are some of the key issues driving these movements?

Sandy Ho

I think... there can be an understanding that disability community issues are rarely prioritized until we see them in the headlines. And by then, you know it's too late, right. Like, by then, people have already died. And I'm thinking about, of course, the pandemic. And I'm thinking about police violence and brutality. And we know that these issues have existed long before Twitter or... long before "mainstream disability organizations" themselves started making their #BlackLivesMatter statements. And I think these are some of the key issues driving these movements.

I would also personally look to what are the principles in the disability justice framework... I think the founders already named and recognized what are the key issues that normally are the ways that ableism is cross-cutting and the ways that ableism and the violence of the systems of capitalism are intertwining, and you know feed off one another. And so... it's kind of hard to twist off like housing, transportation, climate change...Yes, those are all key issues that are driving our movement, but what it boils down to is how these issues are systematically oppressing multiple marginalized people. And then how these movements are also collaborating or not collaborating with folks who had been doing this work.

Alice Wong

If we want to bring it down to an issue, I will say, you know, within the last few years that the abolition of prisons is a key issue. You know, we can think about... the school to prison pipeline. If you think about... carceral spaces, for example. You know that the disability community is still trying to fight to live in the community. And here we are (more than a year into the pandemic) where so many people have died in carceral settings. This is not liberation; this is not justice. This is not a world built and centered on disability justice. Because if it was, we would find ways to create care and give care to the best of our ability, within the community, with all of our capacity. This is one of the principles of interdependence... just because we have lots of high needs, like myself, as a ventilator user, somebody who requires total help. I know that this is not just me. I'm not just a list of all my needs. I think that liberation is when we see the wholeness in each other. Then we can really be interdependent with one another and create communities that are centered on care and love. Which may sound cheesy, but it's not. This is a world, if you really have a wild imagination, we can create it. We can create a world without prisons and without nursing homes. It is only until you dream this that we can get to that place. You need to have these dreams, and disability justice has always been about dreaming and about imagination. And that's how we get free... that is how we get free.

Vilissa Thompson

I think for me, in centering key issues, some of the most rewarding work that I've done has been in Black spaces, because Black spaces get intersectionality already. The worker's movement organizers... understand that the Black experience is not a monolith. They understand that the Black experience is very diverse within itself based on region... They are very transparent in understanding that their work hasn't been inclusive of disability, and they want to be more intentional about that, and they want to learn about disability rights disability justice and the disparity within certain issues like education, housing, healthcare, transportation, access, and so forth. So, for me, being in spaces where people already have a framework of intersectionality makes the work a little easier to do. It makes the work more fulfilling, particularly when I'm in these spaces where the people themselves are disabled. And I think that's something we don't talk a lot about, how many people outside of our – outside of disability community spaces, have these disabled bodies and minds. But they don't self-identify, and there are cultural reasons as to why many people don't self-identify that I don't think we give a lot of room for this with the disability spaces. As a social worker, the way that I engage with a lot of folks comes from that lens which is not necessarily from the activist lens, and as a social worker, we have a phrase called "meeting people where they are." And, when I encounter Black folks who are clearly disabled. Clearly, I mean, they talk about their mental health, they talk about their chronic illnesses to talk about the physical disabilities... But you see that detachment for them from the identity part. It's not my job to criticize them for that distance you know, it's my job to understand what created that space for distance. What created this disconnect, and how to be a part of the connection for them – so that a reconnection can occur... Some of the key issues aren't always the issues that we always talk about; some of the key issues are internal. Acceptance and understanding of our bodies occurs in a very ableist, white supremacy, racist society, and that impacts our understanding of who we are in our fullness... And I don't think that many of us, as disabled activists, do a good job of centering the internal work. We're always talking about the issues, and the issues are so important, but the internal work matters just as much... so that, we have more honest conversations about ableism in certain communities. We have more honest conversations about the disparities that disabled people experience in general, and then it's broken down by race and other identities. That internal work matters so much, and that's what matters to me at this time in my work, and seeing the evolution of it is going from the external to talking about these big issues, but really bringing it home for people so that they have a lens and verbiage to really get an idea of where they fit.

Jen Deerinwater

I feel like I see the most glaring, just lack of collaboration, is between the climate movement/environmental movement, the decolonization land back Indigenous communities, and the disability community. These communities are not coming together the way they need to be coming together. You know, within the disability community, there's a little bit of talk about the climate crisis and how that impacts disability. You know, obviously environmentalists and Indigenous people are working together, albeit sometimes not in the friendliest of ways. There's still a lot of tension, but there is some overlap, and now you try to get all three of those things together, and there's not a lot of collaboration there.

All of the disability rates that I could find for Indigenous people on a global level were anywhere from like 20%, up to a little over 50%. You know, I mean that's staggering and that kind of goes back to what I said earlier. No one is just genetically predisposed to becoming disabled on a group level like that. And so, this is clearly a by-product of genocide and colonization, and all these things. And for Indigenous people, a lot of that is connected to environmental degradation. I'll use my reservation as an example. You know we have issues with large scale chicken farming on our reservation now, so large-scale chicken farming is polluting our waters. And we're already in Oklahoma, which likes to boast about being, you know, the pipeline crossroads of the world. We've got so many gas and oil pipelines connecting throughout the state. I don't think we're still the most seismically active at this point, but for quite a bit of the late 2010 decade we have been the most seismically active state in the continental USA because of the wastewater injection wells in the ground from fracking and gas and oil production. Our largest earthquake in the state was in 2016. It was actually over Labor Day weekend when the dogs were let loose on our people at Standing Rock. That same weekend was the largest recorded earthquake in Oklahoma, and the Osage Nation had to declare a state of emergency. I grew up with tornadoes. I grew up with ice storms. I didn't grow up with earthquakes. That is not normal for where I am from. That is absolutely because of environmental degradation. I look at communities in Canada – so-called Canada, I should say... because that is Indigenous land. But in so-called Canada, for example, the city of Winnipeg... I read this great book, it's just a very small thing, but it's like full of information, it's called Aqua duct, and it's all about how municipal water happened in Winnipeg, and it was the lake Shoal community... all of their water, the government came in, took their water, and routed it down to Winnipeg so that the mostly white urbanites of Winnipeg would have water, but now the people of that community don't have water. As you know, a lot of the reserves in Canada are under boil water advisories.

... I talked to Kera Sherwood O'Reagan. And she's Maori. She does a lot of work around climate and Indigeneity and disability. They have a lot of coastal erosion and you know rising waters that they're dealing with in Aotearoa or New Zealand, as it's called... and she talked to me about how dairy farming was a big part of local industry down there. And we know dairy farming contributes to greenhouse emissions, yet people can't live off the land anymore the way they used to, so they have to take those kinds of jobs. You know, when I talked to relatives down in southern Louisiana, the tribal lands down there, or throughout the area, are called cancer alley. It is a very similar thing there; they can't live off the land anymore. You know, fishing... those sorts of things. I's getting harder and harder to make money that way. You can't really feed your immediate family off that. Like, literally go and catch the food and bring it home. So, a lot of them are being pushed into oil and gas. You know, it's like one of the very things that's killing them is also the only way they can feed themselves. So, I don't know. To me, I just don't understand why these movements aren't working together. Well, I guess I do understand why they're not working together. It's ableism, racism, and colonialism. But they should be working together.

Also, I've been thinking about the United States' Trust and Treaty responsibility and how they are not meeting that responsibility and how that has put us in a situation where we've had the highest rates of COVID contraction and death. We are still getting sick and dying. This is still happening, I know people who are still losing loved ones, even though 71% of Natives live in urban areas. There's been a huge push to vaccinate our relatives on our land, on the reservations and tribal villages, but there's been very little work to vaccinate us in urban areas, even though this is where most of us live. You know, and that is a Trust and Treaty responsibility the United States government has in relation to us. Like, the Indian Health Services is a Trust and Treaty responsibility. It is not free health care; it is health care that our ancestors negotiated through the loss of land and life. You know, whether I am on my reservation or I'm sitting here in DC, I still have a right to that health care. I still have a right to all of these services and things, but they're not happening. And I've been thinking how all of these different issues go together. I've done some, webinars and talks on transportation, and on disability accessibility, and I've been thinking about how do you have paratransit or disability accessible transit on lands that don't even have roads? How do you offer telehealth, if you are in lands that don't have telecommunications infrastructure? You know, even for urban Natives. How do you access telehealth, how do you access distance education or work, if you can't afford a smartphone, a laptop, you can't afford internet? One of our urban centers in Baltimore... it's called Native American Lifelines. They actually had to set up a room in their office after COVID, and we had to start quarantining. They had to set up a specific office for our relatives to come in and do telehealth appointments because not everyone had internet or phone service to do that in their own homes. And because libraries and community centers closed.

Disability Justice and the Academy: Activist Critiques

NE & MM: What critiques can your activism offer to academics of Critical Disability Studies as well as to the disability rights movement?

Alice Wong

I'd just like to say that one of my particular dreams issued to the readers of the audience of this piece... they're clearly academics. You know, I think there's a lot of research that happens by scholars that are not part of that community, and... oftentimes they justify it or split those communities. It is research, as a destructive process, that jeopardizes the work of community-based scholars, people in the movement, people in the local communities that don't consider themselves a scholar, but they are somebody with that lived experience and a lot of knowledge... but not the kind of knowledge that is traditionally thought of as knowledge. A more porous academy that really does partner with and center people who have all kinds of experiences that doesn't require a PhD, to be honest. And I think there's a long way to go to really respect the knowledge production that takes place outside of the academy and to honor and bring in people, to partner with them respectfully, in order to create better work. And I think this is what's really necessary. Because the academy needs to be transformed as well. It is not a place of liberation. It is not accessible. It is an ableist house... that's why I did not finish my PhD. I just want to put that out there because I do believe that there is hope, and you know, it does take, I think, knowledge with the privilege, to use that privilege, right? For those that do know better, for them to really make sure that they ensure that people with all kinds of experiences and knowledge are part of that process.

Sandy Ho

As somebody who has had the experience of also co-teaching disability studies and disability policy classes, whenever a student cites, you know, whether it's a "Ramp Your Voice" blog post or a DVP (Disability Visibility Project) podcast or an intersectionality YouTube video, I get excited, because that's saying, you know, that we are transforming knowledge and how it is carried through our community and shared... As the academy is looking to do better, it can also look inwardly at the multiple marginalized, disabled scholars, who are trying to do the work. I'm thinking about folks who are in the academy and within the system who are trying to push their peers and colleagues to do better. And not just produce, not just through the work that they produce but in the practice as well and how they teach and how they are trying to prepare students of this generation and future generations... It doesn't need to be as manic and harmful as it was for some of these folks who did go through a process of getting their PhDs. In that process, we are all trying to achieve collective liberation.

Vilissa Thompson

I'm not in academic at this time. I do plan to go back for a PhD in a couple years, but in the space that I'm in (as far as social work), I've been seeing a shift in conversations about the way we discuss numerous things, particularly being more inclusive of the disabled experience within the curriculum. I went to grad school 2 years ago for my Masters and remember some of the outdated language that we were using at that time. And how I understood that, when it came to working within social work that I will have to find jobs that are more accommodating or make my own power. Which is what I did with the latter. And that's due to limited access, when we think of traditional social work, we think of case managers and the like. And a lot of those jobs require you to be out in the field. And the field is not always accessible for people who are using wheelchairs, or those who may not be able to drive due to certain disabilities, and other transportation limitations that our community faces. So, within this scope of work, it's been very impactful to see not only colleagues, within academia and outside of academia, but also the students themselves, really wanted to be more intentional as to how they can become better social workers for the community, regardless of the type of work that they do. I was talking to students at a university last month, and March was Social Work month, and they wanted to know how to be better out in the field. And, how to be supported if you are a disabled social worker, a disabled student in the profession. And how to be more impactful within your program in what you need as a student, but also what you leave behind, once you graduate.

And I think that the shifts, within academia and outside academia, are so important, particularly for the areas where disability can be encountered. A lot of people in our community do have horror stories about social workers and therapists and other members of the helping profession as well as within the medical profession. And these are the realities that we face. And those are the stories that I bring to my colleagues, because again, as I said earlier, that's the privilege that I have. To be able to be loud and outspoken about the harm that is being done. . . So I think that for me, I take it very seriously. The responsibility that I have to utilize my platform in whatever space that I am in. To really get people thinking about things like I was saying earlier, the internal versus external, which is really the micro versus macro and really showing the bridge of the two. I think this is very important. And I think that's for me been a defining moment in the work, showing and creating these bridges. Showing how we have always been connected to each other. That, no matter what movement space that you're in, there have always been disabled people there. Whether they've been able to be loudly disabled or outwardly disabled, they have always been there.

Jen Deerinwater

I feel like I should preface it by saying that I have never taken a disability studies class, and to the best of my knowledge that was not anything that was offered at any of the universities I went to for undergrad and grad school, just like Native or Indigeneity studies, were not offered. So, it's something I'm still new to, and I haven't been in academia in 10 years either. So, you know that's not a world that I work in and I'm not a student anymore. And so, I feel like I'm not the person to answer that. But I think that there are a lot of opportunities there, and I am just kind of waiting to see what happens. I am also, at times, very leery of academia. You know, from my own experiences of sexual harassment, gender-based retaliation, blatant ableism, and anti-Native racism – like, I've experienced it all firsthand in my own experiences in academia. And then, we also have to remember who funds, academia, like who's funding it? You know where is the money, where's the money and resources coming from? Whose stolen land are universities on? How many stolen ancestors and sacred items are in university collections the world over? So like I'm very skeptical of academia, in general, I feel like it's education as part of enforcement of institutional oppression, and so I'm very leery of academia, and I'm a big book nerd though, and I am just intellectually curious and I think education is important, so I'm still trying to hold on to some hope there. . . . Also, I think sometimes, you know, these sorts of buzzwords, like intersectionality and decolonization, they start off in good places; they come from grassroots movement folks. They come from the people firsthand experiencing this, and then they just slowly get co-opted over time. Land acknowledgments. Amazing example. I can't speak to anywhere but the USA. The so-called USA on this one, but no one was doing land acknowledgments pre-Standing Rock here. No one was doing that outside of the Native community. Honestly, I haven't seen any land acknowledgments in disability advocacy spaces. Disability Justice there has been some, but like, the larger disability community? I've never seen it at anything. So, I mean like right there, the disability community hasn't even got to that point of meaningless grandstanding in my opinion.

But for me, I mean you know like a land acknowledgment... great your university acknowledges that you're on x Indigenous land... but are you giving that land back to the people? Are you giving it back to the tribal nation? No. How many of our ancestors are sitting in a university collection somewhere? You giving those back? How many of your museums have our artifacts? Our sacred items in them? Are you giving that back? You know, there's a big push to try to get Harvard University to hand back our stolen ancestors to our people. You know, and this is unfortunately not just something Indigenous people suffer. This is something Black, brown, people from across Asia, you know, Indigenous like the world over have suffered and still suffer. So, I don't know if there's really a way to make academia de-colonial. I don't know if that's possible. Just because of the inherent nature of the way it operates. The way that it is funded. The way people choose to go to school, how you fund your education...I think that there could be some good individuals... there are good individuals doing good work, but that systemic level, it goes back to, like: Is there a way to reform the US government? Nah. It's always been based on genocide and enslavement and imperialism and all these awful things, so I don't know. I would like to think there is, but I don't think there is. Now I think there are absolutely ways people can educate themselves and educate others in their communities without having to be in academia.

The Future of Intersectional Activism for Disability Justice

Alice Wong

I would say going back to the principles that were founded by Sins Invalid. There's a whole disability justice primer that I hope that the whole round table will include as a footnote as homework for people... and I would say that liberation is the goal, the liberation of justice, and I think that you know, that's an issue, it's what we're striving for...

Jen Deerinwater

So for me, I'm just like there are so many opportunities across movements to be working together. Yeah, so like when I think about, as an Indigenous person, when I think about decolonization that to me means everything. That doesn't just mean land back. It means the end of ableism, the end of colorism, and sexism, you know. All of these messed up values that have been forced upon us. Like, we have got to get rid of that. That is what decolonization is for me. It's getting rid of these toxic ideas of who we are as people and who other communities are as people and starting to work together and working to repair the hundreds of years of toxicity and genocide that have occurred.

I think there's absolutely room for disabled and Indigenous people to work on things like the eugenics movement. For example, it's still legal in this country on the federal level to sterilize disabled people against our will. While the US government has also for a very long time been sterilizing or forcing people on too long-acting birth control, who are Indigenous, Black, or brown. You know, there are just so many opportunities for us to be working together, but I think it also takes us all understanding a justice-minded framework. And I think you can see right now where communities and movements are splitting just over things like the police. Some people want reform, and some of us are like: Hell no! No more cops! Defund now! I think that that's where there's also a disconnect in not understanding the true large scale insidious nature of all of these isms and phobias and oppressions, and that it's not just one or two bad politicians or one or two bad cops. Know it's a system. It's a system that was created to work exactly like it is. Like it's not broken. It's working how it was intended to work. And I think a lot of people still haven't caught up to that. And I think a lot of people don't understand why someone like me, for example, is so goddamn angry and fed up. Like, I'm done asking for crumbs, I'm taking what's mine, and I think that's also where we have disconnected movements. It's just that some people with a little more privilege don't seem to understand how you just reach a point one day where you're like, enough is enough.

Vilissa Thompson

When it comes to these conversations, people have to be comfortable with being uncomfortable. People have to be comfortable with being de-centered. People have to be comfortable with not being in the spotlight and moving out of the way and being a backdrop. And I think that a lot of that de-centering is a lot of ego. There is a lot of taking stock of privilege and an over-visibility, versus under visibility and really seeing what we can do now in the present so that 50 years from now I want disable people of color to be at the front, I want us to be seen. I want us to feel safe. I think that's the thing that a lot of Black civil rights activists, activists like myself, always say: We don't feel safe in any community, because there is no safe point. And I really want the disabled activists of color that are nipping at our heels to feel safe 15 years from now, or safer than we do now. . . I leave this legacy to where those who are coming up can take that baton and take it further than I can even imagine that any of us on this call can imagine right now. And really re-shape what it means to be disabled and of color, and you know, in my case, what it means to be disabled and Black, and really having these conversations that we're not able to have because we're doing things one by one, and we can barely get to one or two. And really create this vision and hope and care and love that is missing in this space that we're trying to create today, but I hope becomes reality. Fifty years from now, 100 years from now, for our community and those within them.

Further Resources

Disability Intersectionality Summit: https://www.disabilityintersectionalitysummit.com/

Vilissa Thompson: https://www.vilissathompson.com/

Ramp Your Voice: http://www.rampyourvoice.com/black-disabled-woman-syllabus-compilation/

Teen Vogue: Center for American Progress, CNN, Prism, Huffington Post, Vilissa's website

Alice Wong

Disability/Visibility Project: https://disabilityvisibilityproject.com/ and https://disabilityvisibilityproject.com/ada30/

Jen Deerinwater

Crushing Colonialism: https://www.crushingcolonialism.org/ and https://truthout.org/articles/im-native-and-disabled-the-government-is-sacrificing-my-people/

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Disability and Disablement in Settler Colonial States: Indigenous Perspectives of Disability Since Time in Memorial

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Sean Hillier and Jessica Vorstermans

Contents

Abstract

This chapter is a journey of learning, focusing on the experiences of Indigeneity, disability, and disablement in the settler colonial states of Canada, Australia, New Zealand, and the United States and how we collectively can work on healing or reconciling. We start by taking up colonization, which for many settler states share numerous elements and functions (removal from land and forced relocation to reserves, residential schools, and removal of children to "care" by the state). We take up three main periods of time: First, learning about notions of disability prior to widespread European contact. Second, using an intersectional lens, we will learn about the initiation of colonization and ongoing processes of colonization impacting Indigenous Peoples in settler states, using the life span as a way to organize this section. Finally, we conclude with our journey toward healing and knowing by discussing the lived and imagined futures that return to Indigenous ways of being, knowing, and relationality that resist Western and settler-state productions and reproductions of disability and disablement.

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Introduction

Kwe (Hello), we welcome you on this journey of learning and healing with us. The journey we are embarking on through this chapter will focus on learning the experiences of Indigeneity, disability, and disablement in settler colonial states, Canada, Australia, New Zealand, and the United States, and how we go about healing (or reconciling). We will bring you along the process of learning about colonization, which for many settler states share numerous elements and functions (removal from land and forced relocation to reserves, residential schools, and removal of children to "care" by the state). In order to do this, we will take up three main periods of time: First, learning about notions of disability prior to widespread European contact. Second, using an intersectional lens, we will learn about the initiation of colonization and ongoing processes of colonization impacting Indigenous Peoples in settler states, using the life span as a way to organize this section. Finally, we conclude with our journey toward healing and knowing by discussing the lived and imagined futures that return to Indigenous ways of being, knowing, and relationality that resist Western and settler-state productions and reproductions of disability and disablement.

Natalie Clark (2016) argues that Indigenous intersectionality, what she terms red intersectionality, has been ignored in the wider body of literature on intersectionality. She tells us that "this knowledge of the interlocking arteries of colonialism has always been part of our truthtelling" (p. 49). That as far back as 1883, Indigenous activists like Zitkala-Sa and Winnemucca were struggling against violence "on the land and the body" (p. 49) that took up ways that this violence is enacted in particular gendered and aged ways. We work from this conception of intersectionality and add to it the category of disability, in order to further deepen our understanding of the experiences of Indigenous Peoples in colonial states. Importantly, we must also understand that an intersectional lens must take up Indigenous Peoples' connection to, and at times displacement from, their traditional lands. We also cannot talk about intersectionality without recognizing the inherent sovereignty, and resulting power dynamics, that Indigenous Peoples have to the places in which they are located that impact their relations with and to one another, whether they be Indigenous relations or settler ones. This chapter troubles, or problematizes, Western conceptions of disability and works to center ways that disablement is produced through colonization and its attendant violent practices, and ways that Indigenous Peoples are reclaiming conceptions of disability, and the centrality of land and sovereignty in Indigenous struggles against disablement.

We come to this work with our own ideas, worldviews, and lived experiences. As such, instead of locating oneself within the research to identify biases, Bastien (2005) and Lavallee (2009) argue that we do so in order to connect with community and to understand our own way of knowing which may differ from that of the community or peoples we are researching. It is for this reason that we position ourselves as writers of this paper but also as the readers of the works listed herein. Dr. Sean Hillier is a queer Mi'kmaw scholar and registered member of the Qalipu First Nation and grew up on the southwest coast of Newfoundland. However, he has been residing in Toronto for the past decade. Sean's collaborative research program spans the topics of disability, aging, living with HIV and other infectious diseases, and antimicrobial resistance, all with a concerted focus on policy affecting health-care access for Indigenous Peoples. Dr. Jessica Vorstermans is an able-bodied white settler who grew up in an intentional community of people with and without intellectual disabilities just north of Toronto. Jessica's research uses critical disability theory and the lens of intersectionality to complicate North-South encounters engaging impairment and disablement. Her work engages community-based research, centers the perspectives and desires of those in the South, and takes up equity, critical care in community and North-South relations.

We, the writers of this work, are located in Toronto, Canada – also called Tkaronto. This land has been care taken by the Anishinabek Nation, the Haudenosaunee Confederacy, and the Huron-Wendat. It is now home to many First Nation, Inuit, and Métis communities. We acknowledge the current treaty holders, the Mississaugas of the Credit First Nation. We must preface this work with the understanding that while Indigenous Peoples across Canada and other settler colonial states have shared experiences, ontologies, and understandings of the world and our relationship to and with it, we are also diverse among and between ourselves. The information that flows through this chapter is put forth in a good way and is not meant to represent Indigenous Peoples widely (or pan-Indigenize), but instead we rely on specific examples from our own experiences and what has been previously published to provide you a narrative description of Indigeneity, disability, and disablement. Specific understandings of disability from one nation may be at odds or run counter to the teachings and understandings of another and all run counter to Western understandings of disability that have become normatively embedded within mainstream settler society.

Disability Prior to Contact

To start our journey of learning together, we detail the contextual aspects of disability prior to contact, the ways "disability" was constructed, responded to, and imagined. Guiding you through the first part of this journey, Sean contextualizes through a short story of his own learnings in relation to disability as we start our discussion in Canada.

As a Mi'kmaw person, when I was completing my master's degree in Critical Disability Studies, I struggled not having any Indigenous faculty. A gap in my knowledge became apparent as I started to work on my major research paper, which took on a critical discourse analysis to understanding mental health and additions within First Nations in Ontario, Canada. It became apparent quickly that I lacked the key understanding of how my people, or Indigenous folks elsewhere, viewed and represented disability. This lack of knowledge drove me to books and peer-reviewed articles, where I found many non-Indigenous voices explaining "Indigenous disability" within a Western worldview. During this time, I was living in downtown Toronto and want to take up the responsibility of discovering this knowledge; however, it seemed insurmountable given my circumstances. However, after searching, I was able to meet with a Mi'kmaq Elder in Toronto. During our meeting, I ask how the Mi'kmaq view and understand disability; after a long pause, they started talking – this is the only question I ask. They never once use the word "disability"; instead, they tell me several stories. I listen patiently and absorb all I can. I reflect for a week on what I have learned, and while the Elder's answer was not a direct response to my question, I was left with much richness from our connection. Today, I take the learning from that day, and the other teachings I have, to understand disability in a multitude of ways. First as Mi'kmaq, we believe in living a good and balanced life. We do this by living in harmony with all people and creatures; we are one with the earth we inhabit. Living a balanced life means respecting and protecting one other. I have come to understand that the creator has created us all with gifts we bring to our families, communities, and the world. I place this understanding with the teachings of a symbol that represents the Mi'kmaq people, our national flag, with its wapék (white) backdrop, denoting the purity of creation. I have come to understand the birth of all people of creation as pure: that we have responsibility for each other. People born and living with disabilities are gifts of creation, and we have a responsibility for and to them and in ways their gift brings us all together in their care and protection.

Similarly, in Manitoba Canada, the Cree use the word *kakanaticichek* meaning "the gifted ones, the special people," with there being no word in the Cree language for disability, impairment, or abnormality. "The Creator put these people here for a purpose so that we will learn from them; they are our teachers. No one is considered abnormal in our culture" (Shackel, 2008, p. 37). We have accounts from different First nations across Canada related to traditional understandings of disability. For Wiebe and Johnson (1998), they note in their book, "The old man said, to have been born imperfect was a sign of specialness... The old man explained carefully that in the old days, if a child came with a hare-shorn lip, it wasn't a terrible thing or a hurtful thing; it meant the child's soul was still in touch with the Spirit World" (1998, p. 243).

When examining the Australian context, the Aboriginal Peoples of those lands note there is no word for disability within their language and was therefore not something they were familiar with using. This is not to say that there weren't specific words for different impairments, but there was no broader word for disability; this was because people who had impairments were not separated from the rest of their community for any difference they may have had. For in traditional Aboriginal communities, people with disabilities were not generally excluded or stigmatized within their communities. Independence was not seen by many communities as a major issue, and communities rallied around those who required greater help, as the collective welfare of the community was seen as a responsibility for all. Traditionally, some communities may have viewed people with disabilities as something special or perhaps this was the result of a past wrongdoing (First Peoples Disability Network Australia, 2020). Accordingly, a person may have been named after their impairment, such as a person who was missing a leg being named "one leg." However, the primary ideals are that people were loved and accepted by their communities, and the "limitations" we may label today were something the community supported and nurtured.

The Māori Peoples of New Zealand also have traditional approaches to viewing disability. Māori teachings emphasize respect for the whole person and for all living beings, including teachings that uphold dignity and promote values such as nurturance, hospitality, and inclusivity (Bevan-Brown, 2013). Huhana Hickey, a disabled Māori activist, notes that "Māori with disabilities were traditionally cared for by their whanau (extended family)" (Senier & Barker, 2013, p. 126). Senier and Barker (2013) explain that in cases in which traditional communities perceived impairments as distinct, they sometimes regarded particular impairments as especially valuable; for instance, kāpo (blind) Māori were held in high esteem, as were Navaho people who might now be labeled as autistic. Māori in the ancient world who had a vision impairment were people with the power and status of deities. They were known for the talents that they possessed, not for what they didn't have. They also held great knowledge and shared that knowledge with others (Bevan-Brown, 2013).

For Indigenous Peoples in the United States, what constitutes a disability, causes of disabilities, and appropriate interventions vary widely depending on the respective culture. In the Navajo culture, the emphasis is on the cause of the disability and traditionally focused less on the symptoms influencing the choice of interventions. Traditionally, for many Native Americans, there was no word for disability within their language; instead, they place emphasis on their sacred foundations as explanation for all experiences and folks born with body and mind differences which were accepted as gifts from the creator (National Association of Friendship Centres, 2006). This has a direct relation to the non-acceptance by some communities of external causes of impairment. Melissa Tantaquidgeon Zobel, Medicine Woman for the Mohegan Tribal nation of Connecticut, says: "traditionally, disability is not seen as such [because pre-colonial societies] had established means of caring for and absorbing disability" (Senier & Barker, 2013, p. 126). This is also exemplified by the Hopi people who believe that a person born with a condition that inhibits mobility but can still contribute to the functioning of the community is not seen as being disabled. However, since colonization, a person consuming alcohol is seen as being disabled due to their inability to contribute to the overall welfare of the community and may be shunned (National Association of Friendship Centres, 2006).

There is no one answer to traditional approaches to understanding or viewing disability. We know there was great diversity for how disability was viewed and responded to. However, an underlying facet for all was the idea that Indigenous Peoples did not label disability as they do today. And in almost all circumstances, it became the responsibility of the community to assist people in bringing forth their gifts, if they were unable to do it for themselves. However, for some communities, the initiation of colonization has all but destroyed the traditional knowledge necessary to come to understand their traditional approaches to disability. There may be Indigenous communities who still use these approaches and understanding within their communities. However, we know that this not the case in many Indigenous communities, where settler colonialism has permeated deeply, forcefully stripping away traditional teachings and work to counter intersecting oppressions. Therefore, it is more important than ever that settlers continue to center Indigenous Peoples' knowledges and ways of knowing and being so that they can continue to pass this along to the next generations.

Initiation of Colonization

We continue our journey of learning by examining how disability has been re-imagined and reconstituted through state-led processes of colonization. This section should be read through a lens and understanding of the non-negotiable rights of Indigenous nations and the sovereignty they possess and the centrality of land in understanding ways that the violence perpetrated by colonization has been and is structured, as articulated through a framework of red intersectionality (Clark, 2016). I, Jessica, a settler, enter into this journey with care and in a humble way. I write about colonization as an ongoing process that perpetrates violence and trauma on many bodies constructed as different, less than, unruly, subhuman, and not worthy. I write from within and against this system that I benefit from as a settler. I write from the complicity of my whiteness. This journey will take up experiences of intersectional violence across the life span, emphasizing ongoing violence and trauma of colonization, not as history but as ever present and ongoing in the lives of Indigenous Peoples in settler states (Canada, Australia, New Zealand, and the United States), with a particular focus on the Canadian experience.

Colonization in settler states has many points of similarity and departure (Wolfe, 2006). Settler colonizers across states operated, and operate, in hauntingly similar ways: using disease to disable, maim, and kill Indigenous Peoples, the violent stripping of Indigenous Peoples from their land, the apprehension of Indigenous children into state custody, and the exertion of control over reproductive and familial domains. This is all rooted in anti-Indigenous racism, ideas of inferiority, and sub-humanness which disables all Indigenous Peoples and produces impairment in many different ways (Hollinsworth, 2012). Indigenous conceptions of interdependence and relations as rooted in sacredness are violently pushed aside, leaving "soul wounds within the minds, spirit and bodies of Indigenous peoples as well as within whole communities, soul wounds that continue to be felt from one generation to the next" (Norris, 2014, p. 73).

The racism, violence, and trauma of colonization have built a deep system of disablement for all Indigenous Peoples, regardless of whether or not they have an impairment (Hollinsworth, 2013; Meekosha, 2011). Ethnographic research with disabled Indigenous Peoples in Australia asserts that racism enacted by the state has constructed disability and disablement (King et al., 2014). Disablement can be understood as the processes of (neo)colonialism, (neo)imperialism, and capitalism that create the material conditions and social relations of disability in particular ways for particular bodies (Gorman, 2016; Grech & Soldatic, 2016). The centrality of the destruction and dispossession of land as central to the disablement of Indigenous ways of knowing and being in the ongoing projects of colonization in settler states has to be understood and centered in any analysis and engagement in this area

(Jaffee & John, 2018). Using the lens of red intersectionality (Clark, 2016), the ways in which Indigeneity and disability are intertwined and constructed make it impossible to parse out the oppression built around each separate identity. Hollinsworth (2013) explains: “it is not possible to extricate Indigenous experiences of ‘having a disability’ from the often-disabling experiences of being Indigenous in ‘white’ Australia” (p. 603). The mutually constructive nature of oppressions must be highlighted, as we are unable to parse out where oppressions begin and end but instead how they work in mutually constitutive ways. The intersections of racism, ableism, and disablement are painfully made known when we take up lived experiences of Indigenous People living with impairments. The experiences of racism, ableism, ageism, cisheteronormativity, and disablement are the lenses through which we can understand lived experiences of Indigenous Peoples in settler states, and Indigenous People’s resistance to these oppressions.

This part of the learning journey works to center how oppression and marginalization operate at the intersections of Indigeneity and disability over time and space in settler states. Oppression deeply structured in settler-state policies and practice of eugenics are an ongoing chilling example of ableism and racism working to eradicate Indigenous Peoples through the control of Indigenous People’s reproduction and Indigenous children: the construction of Indigenous women as less than, feeble-minded, unfit to parent, discourses of mental disability, and ways that the state enacts control. This sexism has been a central part of settler colonialism and can be traced from contact to current times with the huge numbers of Indigenous women, girls, and 2SLGBT folks who have gone missing and murdered in Canada (National Inquiry into Missing and Murdered Indigenous Women and Girls, 2019) and the apprehension of Indigenous children into state care. The residential “industrial” school system in Canada was administered by Christian denominations, mainly Catholic, Anglican, Methodist, and Presbyterian, where 150,000 children were forcibly “educated” from as young as 4–5 years old to 18 or 19 years old (Woolford & Gacek, 2016). Physical and sexual abuse was rampant, and children worked menial labor to upkeep of the schools; they were carceral spaces and “often deadly environments” with a minimum estimate of 6,000 children dying in the system (Woolford & Gacek, 2016: p. 404). However, with the ongoing discovery of mass grave sites at residential school locations across Canada in 2021, this number is likely to be significantly higher (Lee, 2021). The extreme disablement and trauma of what Woolford and Gacek (2016) identify as genocidal circularity are felt in generations of Indigenous families in settler states.

Research with Indigenous Peoples living at various intersections reveal the compounding ways in which violence structures their lives. The ways in which Christian dogma organized the violence in Canadian residential schools and worked to restructure two-spirit identity, which went against the long history of Indigenous communities embracing the nonbinary nature of gender and the fluidity of sexuality (Taylor & Ristock, 2011 in Ristock et al., 2019). The shift in this identity, from being valued within Indigenous culture to this value being destroyed through colonial violence, is complex and lived intimately in bodies, forcing them to migrate, often leaving them open to situations of compounding violence. The layers of structural, state, and more intimate experiences of violence are a complex web that structure the lives of two-spirited Indigenous People in settler states, and understanding this complex web of violence must be embedded in an analysis of colonialism and anti-Indigenous racism (Ristock et al., 2019). The rate of HIV infection in Indigenous Peoples in Canada is disproportionally higher than the general population, impacting both women and two-spirited queer folks. High HIV rates in communities are being directly associated with being a "gay problem" that communities must address, reflecting deeply entrenched Christian moralistic trans/homophobic views that are now subjecting queer folks to extreme violence and the further disabling/pathologizing of their bodies (Hillier et al., 2020).

Western ways of identifying, labeling, and organizing impairment are often at odds with the ways Indigenous communities engage with impairment, where difference is not pathologized; instead, balance is sought, with balance being an expansive concept including the mind, body, and spirit; and balance may mean learning to live with a bodily difference, not an attempt to eliminate the difference (Lovern, 2008). An impairment is not a disability if lived in community and one's needs are taken care of by one's kin and understood from a holistic framework, which sits in opposition to diagnostic and measuring tools of settler states (King et al., 2014). Indigenous communities are diverse and construct disability in many different ways: what is labeled as disability in one community might not be in another. Complications arise when health and disability systems label Indigenous patients as "non-compliant" in their interactions, when the reality is that Indigenous Peoples are operating in a system that does not honor traditional ways of knowing, being, and doing (Hollinsworth, 2013). In qualitative research with Indigenous Peoples in the settler states of Australia and New Zealand and the non-settler state of Mexico, Rivas Velarde found that disability was not an identity claimed by participants but instead was forwarded as "Western or 'doctor's' language" (2018: para. 25). Mexico is a non-settler state, because "in settler colonial states, the settler population constitutes the majority and thus dominates institutions. When discussing Mexico, the prevalence of intermarriage between settlers and local tribes-peoples led to a new group of people called the Mestizos, and it is this group who constitute the majority and control local institutions" (Rivas Velarde, 2018: paras. 17–18). When using settler-colonial measurements of disability, the data in Canada shows that there are higher disability rates among Indigenous Peoples than non-Indigenous, with Indigenous women more likely to have multiple disability labels than non-Indigenous women and experience what are labeled as "severe disabilities" more often than non-Indigenous women (Hahmann et al., 2017). The social organizing categories of health and disability are much more mutually constitutive for Indigenous Peoples and are not mutually exclusive as much disability work in the West/North theorizes. For example, studies on experiences of pain with Indigenous Peoples in Canada and the United States have shown higher prevalence of pain felt in the body, as compared to those in the non-Indigenous population (Jimenez et al., 2011 in Hahmann et al., 2017). When Western disability theorizing focuses primarily on the social and political forces of disablement, the impacts on the body are erased or marginalized. Studies like these allow for a deeper understanding of the embodied impacts of disablement and racism and ways in which structural oppressions are lived in certain bodies.

Disability Across the Life Span: Intersecting with Indigeneity

When we take up the intersection of Indigeneity and disability in settler states, we see specific ways that the construction of disability and production of disablement take shape in different but connected ways across the life span. These larger socially produced processes live in specific bodies in specific ways. For example, in Alberta, Canada, between 1929 and 1972 when eugenics was state policy under the *Sexual Sterilization Act*, we see Indigenous Peoples as over-represented in those who were sterilized, making up 6% of those sterilized while representing 2–3% of the overall population. Further analysis shows that the stated reason for sterilization as "mentally defective" was made in 77% of the cases of Indigenous patients, as opposed to the same reason for 46% of non-Indigenous patients (Grekul et al., 2004). The state continues to pathologize and control Indigenous bodies in 2021 with government social service agents, responsible for the care of young folks, forcing them to undergo painful procedures for the insertion of intrauterine devices (IUDs) in children as young as the age of 10 (APTN, 2021). Similarly, residential schools, across settler states, were created for the purpose of eradicating the "savage" from the child, whereby the "savage," or the Indigenous body, was viewed as and articulated to be a brutal, viscous, uncontrollable, and violent one.

Anishinaabe scholar Nicole Ineese-Nash (2020) reminds us that a social determinant approach to health positions Indigenous identity as being an "at-risk" category for a higher burden of diseases and negative health outcomes. A critical disability lens re-orients the problem as one of anti-Indigenous racism, ableism, and ongoing colonialism by settler states, states rooted in genocidal projects enacting violent trauma that constructs the disablement of Indigenous Peoples. Through this approach we understand how the production of both disablement and impairment are intertwined and cannot be understood separately. Systemic institutional and environmental racism has produced impairments in Indigenous communities, through environmental poisoning and contamination, unclean water, food insecurity, and lack of access to health services including safe maternal health (Hollinsworth, 2013). Intergenerational trauma, stemming from ongoing centuries of violence, has manifested in physical and mental health distress, chronic and infectious diseases, and depression and substance use (Bombay et al., 2014; Wilk et al., 2017) and continues to disable Indigenous Peoples. Those who experienced direct traumas and violence and those in their families who were born after this era still continue to experience ongoing health impacts and impairment.

Childhood and Early Intervention

There exists an inherent tension between Indigenous worldviews, many of which view children as gifts from the creator, and Western systems that focus on early intervention, pathologization, and a medicalized view of disability (Underwood et al., 2019; Ineese-Nash, 2020). Mainstream Canadian disability services are not designed to be culturally safe for Indigenous Peoples, and many Indigenous cultural service spaces do not provide disability services. Therefore, families are left to choose between accessing services that are not culturally appropriate, which typically dislocates them from their community through forced migration or not accessing services at all. This is the "choice" the Canadian settler state offers to Indigenous families. This produces the conditions that place Indigenous children at increased risk of apprehension by the state. The historical roots of Indigenous child apprehension run deep in settler states, through the residential school system, to the adoption and fostering of Indigenous children into non-Indigenous homes that continues today. At the start of the 1970s in Canada, one third of Indigenous children were separated from their families, communities, and culture and adopted or fostered into non-Indigenous homes. This has created ongoing mistrust and fear of settler-state social services and well-founded fears that children will be removed from families if they seek services and supports for the needs of their children (Sinclair, 2007).

Ineese-Nash (2020) foregrounds Indigenous relationships to difference as radically different to the ways the colonial project constructs difference as negative and therefore systems of oppression are built around those who are different. She shows how disability services in childhood promote assimilation, a goal of the colonial project, working to have Indigenous children labeled with disabilities and move closer to settler normativities, denying their culture and ways they live in relation to others and an erasure of seeing differences as gifts. Developmental normativities around independence and self-sufficiency that are embedded in disability services, early childhood services and education are often at odds with the ways Indigenous communities view development and therefore work in a way that is contrary to Indigenous ways of being and knowing (Durst, 2006). Early intervention (EI) in the lives of disabled children, most prominently through health systems, is seen as an important tool to ensure and protect "optimal development" and is utilized and accepted widely, including being enshrined in international human rights law. The Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD) together outline the right to early intervention and obligations of states to ensure compliance (Brown & Guralnick, 2012). But the systems of EI can further the logics and functions of colonization, isolating disabled children from connections to family and ways of knowing and being (Underwood et al., 2019: p. 21). EI logics are antithetical to Indigenous ways of childhood development, where priority is often placed on relational and experiential learning and often take place in environments that do not match their home and cultural environments. Indigenous belief systems are typically centered around the importance of land in health and development, and this is not reflected in EI systems, making them contrary to the needs of disabled Indigenous children and their families (Underwood et al., 2019).

In *Across the Lifespan: Apprehension, police wellness checks and carceral institutions*,

Sinclair (2016) reminds us that the Canadian state has been removing Indigenous children from their homes for generations, from placing them in residential schools to the "sixties scoop" (Sinclair, 2007), to the current shockingly disproportionate number of Indigenous children in the child welfare system, and shows how racial bias and the legal system uphold this racist practice. Indigenous children make up

7% of the child population in Canada, but disproportionately 48% of foster children are Indigenous (Statistics Canada, 2011). Indigenous children are apprehended by the state for intersecting factors around socioeconomic conditions, trauma responses rooted in colonization, racism, and labels of cognitive impairment (Gough et al., 2005 in Sinclair, 2016). Similarly, ostensibly neutral health policy, such as the Residential Southern Placements in the North West Territories, Canada becomes enacted as a violent intervention of erasure that specifically targets Indigenous adults and children with cognitive disabilities through long-term and, at times, lifelong dislocation from families, communities, and land (McKee & Hillier, 2020). Apprehension happens under a justice system that weaponizes a "best interests of the child" test that is stepped in racist and ableist normativities and serves non-Indigenous interests (Sinclair, 2016).

It is also critical to also give voice to the intersections of police violence, disability, and Indigeneity in North America and the responses from community. One of the ways we see oppression in the intersecting identities of disability and Indigeneity is the over-representation of Indigenous Peoples in the state carceral system (La Prairie, 2002) and in police-involved deaths (Stelkia, 2020). In Canada, Indigenous Peoples make up 4.8% of the population but are horrifically over-represented as 30% of the federal prison population, with Indigenous women making up nearly 50% of women incarcerated in federal prison (Government of Canada, 2021). Many Indigenous Peoples who are incarcerated have psychiatric disability labels. Historically, the creation of "lunatic asylums" removed Indigenous people from their communities and exerted settler-state control over specific bodies (Burch, 2016; Oikawa, 2000). Furthermore, Indigenous Peoples are ten times more likely to have been shot and killed by a police officer in Canada since 2017 than a white person (CTV News, 2020; Global News, 2020). During a 3-week period in the summer of 2020, three Indigenous People were killed by police when they called for "wellness checks" (CBC News, 2020). The term "wellness check" is associated generally with situations when police officers check in on someone whose mental health or well-being is of concern. The Centre for Addiction and Mental Health noted that "Systemic racism, including anti-Black and anti-Indigenous racism, has gravely increased the risks associated with experiencing a mental health crisis. These tragic deaths also have a history rooted in Canada's long-standing inadequate investment in mental health." It is important to note that "experiencing a mental health crisis is not a crime, and the response must be a health-care response, not a law-enforcement response" (CAMH, 2020). The situation of policing mental health and addition issues is even more complex given the disproportionately high rates of mental health and addition issues within Indigenous communities resulting from the ongoing effects of colonization.

Older Indigenous Adults

Older Indigenous adults have valid reasons to not interact with the medical and disability services sector, with the navigation of bureaucratic forms and with racist staff being named as barriers (King et al., 2014). This hesitancy to interact with the system has to be understood in the context of historical and current racism, trauma, violence, and institutionalized policies that cannot meet the needs of Indigenous Peoples. Settler-state support for Indigenous Peoples in old age is divorced from Indigenous conceptions of healthy aging, does not address impacts of colonization, and does not attend to cultural and social aspects of Indigenous conceptions of aging and living well (Hillier & Al-Shammaa, 2020). Indigenous older adults are generally removed from their communities, where medical care is limited, and sent to southern urban centers for end-of-life care, where they are separated from their family, communities, and culture before they journey to the spirit world. At both ends of the life cycle, we see disablement manifest in similar ways: Indigenous worldviews are not integrated or centered in state social supports, and interactions with health and care services are harmful and reproduce trauma and do not meaningfully engage with Indigenous ontologies that view life cycles as holistic, rooted in relationality and living well in ways that honor all parts of one's journey, inclusive of impairment without moving to erase or pathologize difference. Part of the ongoing processes of colonization that permeates all social, economic, and political spaces has been through the production of knowledge of disability and impairment from the Western, settler-colonizer standpoint. We will take up the responses to this from Indigenous and non-Indigenous scholars and activists to decolonize knowledge production, theory, and ways of knowing in the next section.

Re-imagining Disability in Indigenous Communities

The last part of our learning journey will be focused on healing and reconciliation. In this section we will take up ways that Indigenous communities are re-claiming disability and resisting disablement. Much of the research centers on or pulls out Indigenous ontologies that support, nurture, and affirm the value of each person, providing the fertile and rich traditional ways of knowing and being that support re-claiming disability and inclusion. Pre-contact ways of being will never sit outside of colonization and the world that has been built post-contact; we have to engage with the complexity that Indigenous Peoples live in our currently constructed world.

Despite the overwhelming oppression and disablement experienced by Indigenous Peoples in settler states, we see the social organization of impairment as embedded in an understanding of difference as positive and as being tied to spirituality. Rivas Velarde's interviews with Indigenous people from Australia, New Zealand, and Mexico reflected this, with a participant explaining, "I remember there was a wee boy who was born and lived for maybe seven years and he was seen as a gift to his *whanau* [family] but his mum would say he was always meant to be here for a reason" (2018: para. 25). This preservation and survival of worldview, of culture, of ways of being and understanding the world are despite the overwhelming violence and trauma of colonization and attempts to break this sovereignty. This is a powerful truth that needs to be centered. Claiming Indigenous identity as a mechanism against ableism is a theme present in the literature – as a mechanism to oppose and cope with the oppression that stems from ableism and disablement (Rivas Velarde, 2018).

Research with the Māori, the Indigenous Peoples of Aotearoa/New Zealand, undertaken through a *kaupapa* Māori methodology, producing Māori knowledge, identified caregiving as central to Māori culture, and Māori research participants centered the family home as where a family member with an intellectual disability should live (Bevan-Brown, 2013). The research elucidated the Māori values of caring for each member of the community, and the idea that learning is a life-long process. These values undergird the reasoning behind the Māori assertion that children with intellectual disability label learn in mainstream, as opposed to segregated, inclusive education. Bevan-Brown (2013) studied Māori perspectives on intellectual disability, blindness and vision impairment, and autism spectrum disorder (ASD). The study "examined for evidence of inclusive and exclusive attitudes and practices. Findings show that while Māori participants' opinions varied, people with intellectual disabilities, ASD, blindness and vision impairment were generally valued family members and many examples of inclusive attitudes and practices were shared" (p. 571). Bevan-Brown speaks about how "for Māori, disability relates to the loss of land, culture, identity, knowledge base, values and language rather than to a concept centered around individual pathology" (p. 573). In this sense, colonialism creates harm and is what "disables" people. The most frequent themes to emerge from participants in the study were "those of *whānau* [extended family] support, aroha [love in the broadest sense] and total acceptance" of the person with an intellectual disability by a person and the Māori community (p. 573).

Research with Māori families identified the lack of appropriately trained special education teachers to ensure that Māori language education was delivered to disabled children and the widespread pathologization and deficit theorizing of Māori children which created systemic barriers for inclusion in education (Bevan-Brown, 2013). Ineese-Nash (2020) calls for a re-imagining of the way that care is organized around disabled Indigenous children, centering their intersecting identity embedded in a culturally safe context that values all parts of Indigenous children and the ways they live with others in their communities.

By inserting a lens with an Indigenous worldview, a Cree or Nehiyaw worldview, for example, educators open greater possibilities of movement to spatial justice, gentleness, and respect in an ethic of inclusion. A Nehiyaw worldview contextualizes what pimatisiwin (Cree for the good life) (Ratt, 2014, in Kress, 2017) means for disabled children and their families, as it gives opportunity for an Indigenous ethical framework to be adapted prior to the offering up of special education, or what is seen as the preferable option, an inclusive education. Finally, this Nehiyaw worldview encourages educators to adopt Kanawayhitowin, an Indigenous foundation of care, and Gentle Teaching.

Knowing one's history and understanding it through the lens of power and oppression to allow for a process of resisting internalization of oppression and a movement toward collective healing are something that the Assembly of First Nations articulated in their collection of stories of the impacts of residential schools (1994, in Bombay et al., 2014). This same journey is something that Indigenous

Peoples can build in resistance to disablement, a process of healing and resistance to ways that the settler state has violently imposed a pathologized construction of disability. What could this complex process of Indigenization look like in and against settler states? What are ways that this process of decolonization can be supported by non-Indigenous disabled peoples and movements? Lavalle and Poole (2009) forward the teachings of the Algonquin and Ojibwe Nations of the Medicine Wheel and explain that other Nations have teachings that are analogous, that can explain this expansive understanding of health, and that sit outside Western constructions of health, especially the narrow focus on mental health when taking up impacts of colonization on Indigenous Peoples. The Medicine Wheel has four interconnected realms: the physical, mental, emotional, and spiritual, and all must be in balance in order for a healthy state to be realized. The deep wounds of colonization have violently disturbed this balance, and healing cannot happen without balance being restored. This healing work must include the ways identity has been fundamentally wounded through processes of colonization, which Lavalle and Poole assert are the root causes of ill health, as conceptualized in a holistic and expansive way and be firmly rooted in native pride, Indigenous understandings of health, and a resistance to internalization of the "undeservingness" that has been produced and reproduced through colonization (2009, p. 279).

Re-imagining relationships of care and reciprocity between disabled and non-disabled Indigenous Peoples in a colonized world is complex task. This complexity stems from the fact that relationships between disabled and non-disabled Indigenous people are rooted in traditional ways of being, teachings, and ontologies that predate colonization but of course do not sit outside of the violent and traumatic processes of ongoing colonization. Solidarities across difference are also the present and future of disability justice. Black, Black-Indigenous, and Indigenous solidarity and decolonial world making are some of the ways that the violence of settler state is being confronted. Indigenous and Black Peoples share interconnected histories in settler states and experience similar violence from the state in terms of "discriminatory hiring practices, racial profiling, inadequate healthcare, lack of access to clean water on reserves, school funding-by-postal-code, warehousing children and their parents in immigration cages, warehousing children in the child welfare system, and higher rates of probation and parole breaches" (Rai, 2020, n.p). The necessity of the work of unmaking of the settler state to a place where Indigenous, Black, and Black-Indigenous people can "breathe and live full lives" has been deepened under the violence and death that COVID-19 has brought to both communities (Habtom & Scribe, 2020).

We end our journey together centering the importance of land. Jaffee and John (2018) remind us that resistance to settler destruction and dispossession of land is essential in our collective resistance to disablement. Disablement cannot be resisted without a meaningful, not additive or extractive, centering of Indigenous ontologies around ways that land is central to life, to relationality and in building a decolonizing disability justice (Invalid, 2019). Disability theorizing, reflected in the disability studies canon, has not accounted for the centrality of land dispossession as a central organizing tenant in the production of disablement. Indigenous land struggles are examples of struggles for disability justice, as struggles against disablement by the settler state, with the Indigenous resistance at Standing Rock being forwarded as a recent and widely known example (Jaffee & John, 2018). We end this learning journey with a generous and humble call to all who are thinking, working, imagining, and struggling in the field of disability studies to center the lived experiences of Indigenous resistance to disablement and colonialism. A red intersectional approach to disability studies is the only path to realizing justice and freedom for all disabled people in settler states (Clark, 2016). We cannot have disability justice; we cannot transform disablement without centering land dispossession and Indigenous land rights and reclaiming of land in our analysis and praxis. Indigenous resistance to disablement will free all disabled people. This is the future, the collective future that we must each work for, from our own lived experience, social identity, and ability to give, in order to heal together and build a world that deserves the brilliance and gifts of all Indigenous Peoples.

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Madness as Response-Ability Against State Terror: A Case Study from Iranian Revolution

33

Sona Kazemi and Hemachandran Karah

This chapter is dedicated to the memory of Darya.

Contents

Abstract

In this chapter, we engage with different forms of atrocities committed against imprisoned dissidents in post-revolutionary Iran. This is just a sample of state violence at large against its own people, from whom it seeks legitimacy and validation. This time, legitimacy is sort by a theocratic state. Through a case study, we demonstrate how madness can be both a product of and a response to state violence, namely, imprisonment and torture. Kazemi interviewed more than 30 former political prisoners who survived torture and imprisonment in the 1980s in Iran, and, now, live in exile, as part of the Iranian diaspora. Their testimonies demonstrate how human resilience can overcome the harshest of circumstances,

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sustain psychological harm, witness the madness and death of friends, and yet manage to carry it all to a harbor. By a harbor, we mean their own memoirs, silence, suicide, drawings, and even witnessing via "madness." We investigate the processes and social relations involved in how some prisoners went "mad" and some remained "sane." Using the Transnational Disability Model (Kazemi, Critical Disability Discourse Journal, 31–63: 2017), we defetishize their disability by demonstrating how madness and sanity can be deliberately created (i.e., socially organized and imposed) from within extremely brutal institutions. Also, we ponder the ways in which madness could be the bodymind's "response" (Sakhi, Ethics and the resistant subject Levinas, Foucault, Marx. York University. Toronto: 2014) to power/violence or a "survival strategy" in the context of asymmetrical power relations (e.g., patriarchy, theocracy). As racialized activists-scholars from the global south, we strive in this chapter to re-articulate disabled-dissident subject's "response-abilities" in the form of "madness."

Keywords

Madness · theocracy · response-ability · political prisoner · Iran · Bodymind · witness · Iranian revolution · transnational disability model · Defetishizing disability

State violence is universal, and its ripple effects on individual lives and communities across societies vary significantly. After the eighteenth century and the arrival of modernity and the constitution of humans as subjects with rights, rights-based discourses legitimately condemn state violence. Equally, political philosophers such as Michel Foucault who are concerned about the state's power to influence its subjects by way of governmentality also gather evidence for indelible markers of torture and violence on broken "bodyminds" of the subaltern. Although these are useful methods to approach and quantify state violence, they do not capture the "madness" inherent to dissidents, especially of the kind that transpires within prisons as highly politicized institutions. Neither are these methods "intersectional," meaning they do not fully foreground inseparable dimensions of social justice struggles at the margins, where gender cannot be fully extricated from race, or race from class, or class from sexuality. In this chapter, we aim at transnationalizing and decolonizing disability (madness) as dissidence while theorizing the state as the embodiment of ableist social relations that injures its subjects. Documenting dissidence this way may come in handy for providing an intersectional locus for expanding the notion of experience within the fields of Transnational Disability Studies (DS) and Mad Studies.

Our interventions stem from Kazemi's decade-long ethnographic research with prison survivors. She interviewed several former political prisoners who survived torture and imprisonment in the 1980s in Iran and now live in exile as part of the Iranian diaspora. This is not to suggest that political torture has ceased after the 1980s in Iran. In fact, since its inception in 1979, the Islamic Republic regime has never stopped imprisoning, torturing, and executing its dissidents and infringing the rights of minorities and women. These claims are well substantiated by international human rights organizations, activists, and a plethora of evidence. For this chapter, however, we focus on the first decade after the revolution. The interviews were conducted in Farsi/Persian and were later translated into English by Kazemi.

Herein, we tell a story of a mad woman political dissident who fought the entire ideological and patriarchal apparatus of the Islamic Republic of Iran (IRI) with her bodymind. We theorize madness as a response-ability against retributive streaks of power and discuss how madness has always been a historical materialist construct, mediated by power relations. Focusing on the story of one "mad" prisoner, Darya, we examine how madness can be both a product of and a response to state violence, namely, imprisonment and torture. Kazemi gathered Darya's life story, reading other prisoners' memoirs and reports which mention Darya, listening to Darya's former comrades and cellmates' testimonies (in Farsi/Persian) firsthand, and reading some notes written (in Farsi/Persian) by Darya herself and collected by a family member. Unfortunately, Darya died not long after being released from prison in 1988, and therefore, Kazemi did not get a chance to interview her. Darya is a pseudonym. So are the rest of the names we use for the participants. The names of the former political prisoners who have written a memoir are cited as is. If they have written a memoir using an alias, we have mentioned the alias in citing their works. If they have used their own names, we too have cited them using their real names.

Following the Transnational Disability Model (TDM) (Kazemi, 2017), rooted in Dialectical Historical Materialism (DHM), we theorize disability (madness) in a transnational context at the intersections of gender, race, sexuality, and non−/citizenship within the theocratic nation-state. In contributing to intersectional and transnational approaches to madness and disability, we move away from mainstream DS content emerging from the United States, the United Kingdom, Canada, and Australia. We retheorize disability by trying to unveil the ways in which discursive and artistic representations of the global northern disabled subjects in disability rights and culture movements in the West have eclipsed our focus on disability caused by violence (e.g., war, theocracy, nationalism, gender-based violence, and torture). In other words, rights-based discourses from the global north can be overdeterministic and essentializing. Consequently, they obscure frameworks such as those deployed by Darya during her uneventful everyday life.

Fully aware of the risk of perpetuating the existing racist discourse of orientalism, which has been described by Edward Said (1978) as a plague that portrays regions outside the West as backward, nondemocratic, and not fully civilized, our intention here is to shed light on the forms of disabling-maddening state violence in Iran, where theocracy rules. Our work demonstrates the agency and politicized identity and subjectivity of Iranian women who participated in the 1979 revolution and resisted the Islamic State that was born out of that revolution. Following Saidiya Hartman's (1997) work – *Scenes of Subjection: Terror, Slavery, and Self-Making in Nineteenth-Century America* – where she refuses to render the slave body as "spectacular" suffering for the consumption of the reader, we also refuse to reproduce political prisoners' sufferings as commodity for the readers' appetite. Instead, we focus on them for the following reasons:

1. To contextualize an individual's experience and illuminate prisoners' living conditions. In order to "see" the prisoners' resistance, we need to know what they were resisting against.
2. To theorize violence not in and of itself, but how it constitutes the subject at the axes of multiple and intersecting social locations, that is, through an intersectionality lens. When we say "intersectionality," we are talking about the intersection not just of identities but of social struggles.
3. To propose the possibility of bearing witness to oppression as a research avenue. Following DHM, we define witnessing as an act that involves politically conscious human beings who can analyze their own roles in the story and also provide the critical context for understanding power relations in order to change them.
4. To rehabilitate the notion of readership shaped by "orientalist" leanings, fetishism, and commodification. Torture narratives tend to get such responses from readers. We offer an alternative account of readership shaped by acts of "witnessing."

Chapter Overview

First, we present our theoretical framework. Then we define state violence and discuss how it operated as a disabling power under the theocratic state in Iran. In order to contextualize the case study, we describe the prisoners' living conditions in the 1980s in Iran including the methods of tortures they endured and how they responded to the ways in which state violence was exercised on their bodyminds. Subsequently, by presenting and analyzing the case of Darya, we theorize madness as a response-ability against crude power.

Theoretical/Critical Constructs

Fetishization

According to Erevelles (2011), when historical and social relations that create disability are overlooked, disability gets fetishized. For instance, one way in which DS (as a field of knowledge and as a discourse) fetishizes disability is by mostly focusing on the contemporary attitudes and barriers that turn impairment into disability and often ignoring the historical, political, and economic conditions that produce disability in global contexts (2011). Erevelles argues that the romanticization of DS in general has prevented us from seeing the roots of the ableist tradition. It seems that understanding disability as a local issue only satisfies the dominant powers in the social relations prevalent in the world. Erevelles argues that "the very category of disability operates as a commodity fetish that occludes the violence of the socio-economic system" (2011, p. 67).

Here, we take this further by arguing that it also occludes the violence of other exploitative social relations and processes, such as theocracy, incarceration, fascism, patriarchy, and political torture. By defetishizing, we mean carrying out a thorough analysis of these categories, in order to unveil the social relations behind their creation and to name the processes that render people disabled through violence. This unveiling process is equivalent to a defetishizing process, which we argue has a revolutionary capacity to produce non-ideological knowledge and praxis. For instance, in the case of the torture survivors' disability/madness, the process of defetishization can take place by listening to what the survivors have to say about their dissidence and encounter with political suppression and by refusing to believe the official narrative that the nation-states impose on us and on those who die and become disabled through state violence. If we aim at producing a form of knowledge based on the material reality under which disabled/mad people live, we need to shift our analysis and pave the way for a revolutionary understanding of disability and its relationship with the nation-state, clerical fascism (Kalantari, 2016), theocracy, capitalism economy, and class society, contextualized within transnational political consciousness and activism.

Bodymind

Rooted in Buddhist philosophy, pioneered by traumatologist Babette Rothschild (2000), and further developed by Margaret Price (2014), Elie Clare (2017), and Sami Schalk (2018), "bodymind" is an approach to fathom the relationship between the human body and mind where they are perceived as a single integrated unit. Both terminology and the notion of bodymind attempt to tackle the duality of body (and) mind and resist the traditions of their separability. The term bodymind is typically encountered in Mad Studies and DS, referring to the intricate and often inseparable relationship between the body and the mind and how these two units cannot be dissected. By "bodymind," Margaret Price means "a sociopolitically constituted and material entity that emerges through both structural (power- and violence-laden) contexts and also individual (specific) experience" (2014, p. 4). Throughout this chapter, we follow Price's conceptualization of bodymind as it pertains to the physical and mental disabilities discussed in the case study. Our goal is to underline the fully integrated nature of the body and mind and the inseparability of the two in the harshest of circumstances such as torture.

Dialectical Historical Materialism

In *The German Ideology* (Marx & Engels, 1932/1998), the foundational conception of DHM was set and constituted as a new method of social inquiry and of recording history. Marx defined historical materialism as a way to understand the material conditions of humans through history. By understanding the material conditions of humans through history, Marx argued, human beings can come to understand their current social and political conditions. He developed DHM as a way to de-mystify human relations and understand history as a result of "sensuous activity of [hu]man[s]" (p. 25). Marx, as he argues in the *Theses on Feuerbach*, believed that knowledge is not separate/separable from the physical body and therefore not separate/separable from the material world. Marx according to his own words was out to change the world, not just interpret it. In formulating the approach of DHM, he developed a new knowledge adequate for creating change "with a centrally-situated agent or subject, without whom no transformative politics would be possible" (Bannerji, 1995, p. 19). From the standpoint of Marxist disability theory, the task is to use DHM to present a dialectical and reflexive understanding of disability, difference, subjectivity, and agency. The key to understanding DHM, and using it, is to understand everything as it relates to history, ideology, and social structures, such as class.

Ebert (1996) describes historical materialism as:

> a mode of knowing that inquires into what is not said, into the silences and the suppressed or missing, in order to uncover the concealed operations of power and the socio-economic relations connecting the myriad details and representation of our lives . . . [historical materialism] . . . disrupts "what is" to explain how social differences – specifically gender, race, sexuality, and class [and to which Erevelles (2011) adds disability] – have been systematically produced and continue to operate within regimes of exploitation, so that we can change them. It is the means for producing *transformative knowledge* (Ebert, 1996, p. 7)

In this project, we do not just look for causality or correlations. Instead, we go beyond what is apparent and examine the case study dialectically. Marx believed that phenomena are "processes" rather than discreet "things" and that every phenomenon is mediated by relations and forms of consciousness in extended circumstances from the past. We adopt this way of thinking, dialectically examining what constitutes reality at any given time and space, and throughout the chapter, we want you to shift from binary, oppositional, and linear thinking to dialectical thinking and historical materialist understandings of contemporary social relations. According to DHM, the dialectical relationship between labor and capital leads to a relation called class. The state, on the other hand, is an organized structure made up of people that serves the interest of the ruling class, meaning the capitalist, nationalist, and in this case theocratic power. Ideology refers to a set of beliefs rooted in a particular social order, held by a certain group of people, to serve the interest of the ruling class while concealing material reality.

Transnational Disability Model

The existing theories in DS are not typically modelled on injury, as a socially caused disability. Although the existing models have much to say about disabilities after they are created, they have said little about why and how disabilities are created or the material conditions and historical processes surrounding their creation. In other words, DS is mostly interested in celebrating disability, embracing difference (Kafer, 2013; Kuppers, 2009; McRuer, 2006), and imagining radical possibilities, including intersubjectivity and interdependence (Fritsch, 2010; Shildrick, 2009) as necessary pillars for a just world, particularly in the global north. This approach is capable of radical possibilities. However, if mere power imbalance causes people to *become* disabled at the hands of the other, how can we just celebrate that as difference and not mark it as a social wound? Besides, the celebratory politics of DS are very much Western-oriented, bourgeois, and not applicable to other parts of the world where people become disabled on a larger scale due to poverty, war, domestic violence, etc. Unfortunately, in the Western academy, one looks at these social practices as a form of violence in certain "cultures" but not necessarily as a *disabling* process.

We argue that an intersectional disability perspective should be deployed that not only engages with disability but also takes into account its close tie with race, gender, ethnicity, class, history, and geographical location within the material context of post/neo-colonial, imperialist, and theocratic states. Such a perspective is radical and anti-ableist because it is neither compliant to normative demands/standards (e.g., white, European, English-speaking, bourgeois, heterosexual, and non-disabled) nor is it complicit in bourgeois democratic agendas. This is what we mean by "transnational": engaging the local and global politics that render racialized bodies disabled by pure power imbalance and violence.

Besides being rooted in the material world, a transnational model means a) we can imagine a world with no borders and avoid trying to impose a universal disability identity upon all disabled people; b) we can resist what dominant DS has been teaching us, which centers "whiteness" and the "West" as its inseparable norms (Chen, 2012; Dossa, 2008; Erevelles, 2011; Meekosha, 2011; Bell, 2006; Gorman, 2016); and c) we can start imagining an organized and diverse group of people with intersectional and community-oriented response-abilities beyond nation-states' borders. d) Relying on Marx's dialectics, TDM can reveal the social relations of disability beyond the instantaneous narrative that the subject conjures, one which can attend to both the social organization of disablement and the situated consciousness/knowledges of, and resistance to, these social relations and power structures. The "what" we try to demonstrate here is how state violence *causes* disability and/or madness on a systemic level, and, equally, the capacity of dissidents in deploying madness as a way to respond to state power, a mode of resistance in all its myriad forms and shapes.

Enigmas and Aporias of Maddening Torture

The following section includes graphic references to topics such as physical, psychological, and sexual abuse and torture.

We are committed to enabling a trueful act of witnessing on the parts of the readers in whatever circumstance they are (e.g., in prisons, in psychiatric wards, in the global south, etc.). Not all forms of state violence are of the same style or degree. For example, in liberal democratic societies, state violence occurs in less direct ways, though still with the same purpose as that of the global southern states: preserving power and disciplining the masses (Blakeley, 2010). State violence targets sex workers, poor people, homeless people, queer, trans, black, Indigenous, people of color, and im−/migrants by hindering their access to humane treatment by law enforcement, health services, and educational institutions. Sometimes, denying access to those essentials could result in death, disablement, injury, deportation, or lifelong trauma. Additionally, transnational capitalism produces social inequalities in employment and access to financial resources, as its inherent logic is exploitation and not "equality" of access to the means and modes of production.

The IRI interrogated, tortured, and executed thousands of people in the immediate years following the 1979 revolution whose hallmark is the 1988 massacre in which approximately 5000 people were executed, most of whom had already served their prison sentences and should have technically been released (Iranian People's Tribunal, 2012; Abrahamian, 2008; Akhavan, 2017). According to numerous accounts, prison memoirs (see Agah et al., 2007; Talebi, 2011, Mesdaghi, 2006; Parvaz, 2002; Parsipour, 1995; Baradaran, 2000), witness testimonies (see Sakhi, 2009), interviews, and the finding of the Iranian People's Tribunal's Truth Commissions, prisoners were held under extremely inhuman conditions, and the torture methods comprised of beatings, sleep deprivation, standing still for up to 72 hours, bastinado, flagellation, and ghapani. Furthermore, "Other forms of torture included: the squeezing of testicles, the infliction of burns with lighters, cigarettes or hot irons, deliberate mutilation, the tying of prisoners to gallows for long durations in winter and summer, and the violent thrusting of a ballpoint pen up a prisoner's nose" (Iranian People's Tribunal, 2012, p. 21). Monireh Baradaran (2001), an Iranian dissident who spent 9 years behind bars as a political prisoner under the Islamic regime in Iran, argues that torture does not stay in prison, but leaks outside and affects every layer of society through what she calls "torture's ripple effect," which fosters fear and anxiety in the masses.

The Iranian People's Tribunal's Truth Commission found that during the 1980s, "political prisoners in Iran, besides getting beaten and abused on a regular basis, were also kept in grossly unhygienic conditions. They were denied soap and the right to showers. The prisons were overcrowded, leading to cases of skin diseases. Cells were teeming with rats; clothes, with lice. One survivor reported that a clergyman came to inspect her cell but would not enter because the smell was so ghastly" (2012, p. 24). Bastinado destroyed many prisoners' feet. One prisoner, Hassan (a pseudonym for one of the former prisoners who was interviewed by Kazemi) mentioned a prisoner whose feet were flogged with an electric cord/cable to the degree that it had turned black, which led to double amputation of his legs. Kidney failure as a result of bastinado was prevalent. There were people with disfigured feet or with a hole on the bottom of their feet caused by bastinado. Tiny toes were a target in some instances. Beatings with electric cables caused injuries including those that of brain. Hassan informed Kazemi about a prisoner who had had a concussion after being hit by an electric cable in the head repeatedly during an interrogation. After that incident, the prisoner showed sign of psychological "disorders," although only in the wintertime.

Mad/disabled people inside the IRI prisons were the living proof of the violence that was committed against the prisoners. The IRI regime, as a young state in the modern era, is an amalgamation of a hardliner religious fundamentalist ideology, carceral statehood, and commitment to corporal punishment. This regime arrested its political dissidents on a massive scale in the 1980s and incarcerated and tortured them for years (Abrahamian, 1999; Makaremi, 2015; Mesdaghi, 2006; Talebi, 2011). However, once people showed "non-normative" behavior or psychological distress, the regime did not commit them right away to psychiatric treatment or any kind of psychological therapy. Instead, it kept them for a long time either in solitary confinement or in a close proximity to other prisoners for two reasons, as we have learned from our conversations with the former prisoners of the regime: 1. to use those prisoners' bodymind as a "mirror" to frighten and threaten the others that this is what you could *become* and 2. to objectify the distressed prisoners' bodymind and turning them into scary objects in order to put extreme psychological pressure on others to recant, repent, submit, and write a letter to condemn their past political activity (read everything they ever stood for as political dissidents).

Prisoners' memoirs are the windows through which we witness what really happened in the IRI's prisons during the 1980s. A few names kept repeating themselves in our perusal of Iranian prison literature from the post-revolutionary era as much in conversations with prison survivors. Many were just names. This meant that we could not always match a name against living evidence such as memoir. Some were executed and some institutionalized in a psychiatric ward and/or ended their own lives after dealing with severe physical and/or mental health concerns. Besides, the Iranian People's Tribunal's Truth Commission (2012, p. 188) found that "Some people went mad in prison; everybody suffered either physical or psychological damage. In Evin and Ghezel Hesar prisons, it was possible to hear people being tortured and their bones broken at night; the witness's jaw was broken during torture." These people had entered the IRI prisons with a non-disabled bodymind and exited it (if at all) with shattered ones. What had happened to them? Who were they? We call them "mad" prisoners.

We use the word "mad" to refer to political prisoners who showed "non-normative" behavior. Non-normative behavior included not speaking with anyone for long periods of time, going nude in public, staying under really cold or hot showers with their clothes on for a long time, becoming incontinent, not caring about personal hygiene, going periodically catatonic and not moving for long periods of time, refusing to eat for days, hoarding food and other things, masturbating in public, cursing guards and regime officials, imitating animals [e.g., jumping like a kangaroo], going against the ward's regulations, being delusional, and being actively suicidal. These behaviors are ones often described by the fellow prisoners Kazemi has spoken with and, in rare cases, by family members. However, madness played out in many shapes and forms. For instance, prisoners perceived their cellmate as mad if she/he gazed into oblivion and remained silent for a long time. Or, one who was engaged in washing themselves too much or was obsessed with cleaning was perceived as someone with "obsessive-compulsive disorder." If someone refused to use the bathroom and, therefore, became smelly and unbearable, she/he was perceived as mad. Finally, one with unrealistic hopes would come across as "delusional."

One of Kazemi's interviewee survivors, Souri, mentioned that what the state terror needed to perform effectively in order to subdue people was to keep them in limbo, a place where contradictions intersected, overlapped, and were reinforced. For example, Souri reported that the regime demanded that they spied on their fellow prisoner, to somehow demonstrate their collaboration with the prison system, and "to participate in the slippery slope of the rational strategic action of survivalism" (Sakhi, 2017, p. 6), if they wanted their own torture to stop. Fledman (1991) argues that discipline divides the prisoner into a body and a self; the self becomes a part of the panoptic machine that applies discipline to its own body. As such, you are stuck between wanting to stop your own suffering and having the power to make your friend suffer. This contradiction, Souri says, is traumatic, per se, because it drives you to a point of confusion and suffering where you might not be able to make an ethical decision after all. The psychological pressure caused by these imposed contradictions, jig-sawing between resistance and submission, sanity and madness, and self and the "Other," was tremendous. Many could not put up with this pressure and gave in to the regime's demands, accepted the conditions, and sometimes even collaborated with their own oppressors in apprehending those who were once comrades. Some responded to this pressure by embracing "madness." Ceasing to exist in a certain form and metamorphosing into something else was a *response* to the non-normative conditions they had encountered.

After more than 30 years since their release, some survivors continued to have nightmares and sleep terrors. Some developed new phobias that they never had before. One prisoner, Nastaran (a pseudonym for one of the former prisoners who was interviewed by Kazemi), for instance, mentioned that she developed a fear of heights that she never had before going to prison. Some became claustrophobic. Some sit on the edge of their seat after 40 years since the days that they had to live in an extremely overcrowded cells packed like sardines. Many developed physical conditions and/or permanent damage, such as spider veins, varicocele, backache, extreme pain in legs and feet, and seizures after going through mandatory standing for up to 36 to 72 or more hours at the time. The psychological effects were also devastating. Some started hallucinating after remaining sleepless for few hours or days at the time. As is self-evident from these accounts, "becoming mad" is a historical materialist process and category – not a pathology. Madness is also a locally created human condition as much as an alternative state of existence, so as to handle extreme forms of dehumanizing torture and prolonged incarceration.

Madness as Response-Ability: The Case of Darya

No doubt, I have, perhaps, gone mad. ~ found in Darya's personal notes (To preserve Darya's anonymity, we refrain from referencing the source, which was given to Kazemi by a member of Darya's family.)

Where there is power, there is also resistance. However, when mass atrocities are narrated in criminal courts, the "victim" is supposed to testify about how power was exercised on his/her bodymind, rather than how she/he *responded* to that power. By "response," we mean resistance, submission, breaking, collaboration, silence, etc. The word "broken" in here as well as the Iranian prison literature refers to breaking inside, submission, and "converting" to what the totalizing system wants from you, Islam in the case of this chapter, and not "psychological breakdown" or a "psychotic break."

One form of torture that produced many mad people was the so-called Resurrection/boxes/graves/machines, the human-making factory" (*kārkhāneh-ye-ādam sāzi*), or the human-making machine (*dastgah-e-ādam sāzi*) that was experimented in Ghezel Hesar prison from the summer of 1983 to the fall of 1984. "Prisoners were forced to squat for hours in boxes in the form of coffins ('the Grave', also known as 'Resurrection'), with Quranic incantations sometimes blared loudly at them, during which they were intermittently beaten and whipped on their heads and faces" (Iranian People's Tribunal, 2012, p. 34).

Shokoufeh Sakhi, a former Leftist political prisoner, who spent 8 years in the IRI's prisons (9 months of which was in the "coffins") and later became the Tribunal's Executive Director, problematized a purely legal approach to justice-seeking. Sakhi argued that the survivors should not be reduced to helpless victims, bearers of the perpetrators' power, inscribed on their bodyminds. Instead, she argued, people, who have resisted the IRI's power in one way or another, should be allowed to say how *they* responded to power. The point, Sakhi (2014) argued, is to acknowledge the "response-ability" of the survivors, however tormented their sense of agency, subjectivity, and autonomy may be. This shift from perpetrator's power to the survivor's response to power is what distinguishes a legal approach to justice-seeking from an ethical approach, argues Sakhi (2017). Therefore, to adopt the ethical approach instead of a purely legal approach, we conceptualize mad behavior of the mad prisoners as a *response* to the forms of power (including ideological components) exercised in political prison. We refrain from pathologizing those behaviors from a biomedical perspective, which usually discount the historical and socio-cultural context in which the behavior occurs. Instead, we strive to unpack those non-normative actions and expressions as a way to understand them, not to diagnose, label, or judge them with a pitiful eye and ear.

We narrate Darya's story, although it is incredibly difficult to pick and choose only one story to tell when there are so many people who perished in the brutal suppression of dissidents in post-revolutionary Iran. We picked Darya's story because it is a representative of many young people's stories who gave up their comfortable lives in the Western countries to join the masses, to participate in the revolution against monarchy, and to make their own history, including Kazemi's father. Coming back to Darya, she was a member of a secular-leftist organization during and after the 1979 revolution in Iran. Darya was a double-major graduate student at a top university in the United States. During the revolution, while in her 20s, she gave up her graduate studies and went back to Iran to participate in the revolution like many other Iranian university students across the world did.

Shortly after the revolution, in June 1981, the newly established theocratic state, which was reluctant to share power with other political parties, cracked down on its opposition on a massive scale. The members, and even sympathizers, of the leftist political organizations, who got arrested, went through unimaginable physical and psychological torture. Darya was arrested in March 1982 and tortured for approximately 7 months, before being tried in a 15-minute-long "court" with no attorney, which sentenced her to 5 years of imprisonment. Darya spent the next 5 years in several prisons in and around Tehran, three of which was spent in solitary confinement. According to one of her cellmates, in the first prison she was at, after her 7-month-long initial interrogation period, which involved physical and psychological torture, she started showing "non-normative" behavior. She would walk for long hours in the tiny cell, speak with herself, refuse to eat or drink, stay awake at night, and go under a very cold shower with her clothes on.

Darya attempted to take her own life four times but failed. Once, she even swallowed a needle, hoping it would kill her, but it did not. M.G. (Kazemi interviewed M.G. to hear about Darya), who was Darya's cellmate during the first 7 months of her imprisonment, told us that their cell was so tiny that three people could not even lie down comfortably in it. She stated:

> Darya was interrogated constantly while bleeding due to her hemorrhoid problem. In her good days, she would teach us French language. On her bad days, she would not fall asleep sometimes for four or five days in a row; She would scream at night. As soon as she would get a little better, they would take her again for interrogation. They may have done terrible things to her. Darya was swearing at everyone. She looked at them from above. She would get kind suddenly. She was incontinent and bleeding constantly. She swore at the guards all the time. She would walk all day and tap her fingers on the wall, as if she was talking to someone. She was moody. She would stare at things for a long time. She was very anxious and stressed. Darya could not sleep. She would jump up and down. If her clothes got wet in blood, she would knock on the door violently and scream.

M.G. also mentioned that they did not have any access to clean clothes or even a spare underwear, never mind a sanitary napkin which is a necessity for women. Kazemi asked M.G. what she thought the first signs of madness were. M.G. who is a nurse responded that the first signs of "madness" were aggression, separation from others, the way the mad prisoners' eyes looked, vanity (*chap ravi* or being too radical), sleeplessness, praying all day and night, forgetfulness, and memory problems.

Darya and many other political activists at the time carried a cyanide capsule under their tongue. This was meant to protect their dignity, their information (e.g., names, organizational ranks, addresses), and therefore their comrades, in case they got arrested and landed in the regime's torture chambers. Because the regime was determined to crush people with torture and break them at any cost, many political activists were prepared to die but not break (i.e., respond to the state by submission). Swallowing a cyanide capsule was not aimed at just ending one's life, although that was the inevitable consequence. It was instead meant to deprive the state of subjugation, torture, extraction of information, and endangerment of other dissidents with that information. Keeping a cyanide capsule under their tongues was a deliberate act of "response-ability" because this was not an act of self-annihilation but a way to protect the dignity of comrades. This was meant to protect comradeship beyond their corporeal boundaries. They prioritized their collective will over individual survival.

The TDM lens that we use here to examine this case is a helpful lens as it does acknowledge the possibility and necessity of people's participation in making their own history. The TDM approach does not end at the exercise of power on the prisoners' bodymind but extends to politically conscious human beings who can analyze their own roles in the story and respond to that power. As such, using a TDM lens rooted in DHM, we argue that it is not just the state that uses the prisoners' bodymind to exercise its power but also the prisoner who utilizes her bodymind to resist the state apparatus. Thus, prisoners such as Darya use their corporeal will to protect the larger cartography of their commitment and mission. This is where responsibility becomes the Transnational Disability Praxis in a collective sense. Darya's response, which is beyond protection of the self who is in pain, is the will to die protecting the community will.

After unbearable torture during interrogation for 7 months, she tried four times to die by suicide which was unsuccessful. The necessity of resistance was encapsulated in her decision to live a life with agency and dignity, rather than living a life with submission which would have reduced her to what Sakhi calls "the survival ego," a self who lives for herself in herself. Sakhi (2014, p. 2), who resisted for 8 years in prison, defines "resistance" as an indication of the prisoner's ability to respond to power, or response-ability. She states:

> resistance is a process, an event, aroused as a response on the part of human beings to something and for something. In this sense, resistance as a response evoked by a human condition, a response to and for, is the manifestation of human's response-ability, a human capacity to respond.

Therefore, as long as the prisoner does not allow the totalizing system to replace him/her with a "system-compatible identity of the given system," that prisoner has resisted that totalizing system. It is at this crucial moment that "madness" should be interpreted as dissent and resistance, because it, in and itself, prevents the totalizing system to metamorphosize the prisoner from Other-of-the-state to Same-as-the-state.

In 1984, Darya was transferred to solitary in Gohardasht, which was known for its horrific solitary cells, absolute silence, and maddening isolation. Darya immediately demanded to get out of the solitary, but the guards just ignored her. Therefore, she went on hunger strike and refused to eat, but that did not change anything in her treatment by the regime. Refusing to eat is an act of resistance and defiance as we have seen in Irish, Turkish, and Indian prisoners who have gone on hunger strikes to resist state suppression or to protest their living conditions in prison. One survivor, M.Z. (We refrain from referencing the source to this blog to protect Darya's anonymity), wrote in her blog that the regime frequently force-fed Darya by putting a funnel inside her mouth while uttering the most malicious and dirty sexual slurs and insults at her. She was never silent. Instead, she was loud and clear and always shouted her demands.

In prison, Darya had a hemorrhoid problem, which got worse during her time in prison as the prison officials refused to provide her with the most basic treatments or even just her own medication. Many people remember her having bleeding problem without access to sanitary napkins, medication, and clean towels. Darya had bulging eyes, which could have been caused by hyperthyroidism or scurvy (caused by a lack of vitamin C). An inmate, who is a nurse, believes that Darya's psychological state must have been affected by her extreme lack of iron. Her blood pressure was often low; and her skin was at times yellowish, which could have been a sign of jaundice or a malfunctioning liver. Darya dealt with several physical and psychological concerns, which underscores the inseparability between the body and the mind. Also, the wounds caused by the state brutality seem as inseparable as the collective will and response-ability emanating from her wounds.

In Gohardasht prison's solitary cells, Darya would not communicate much with others. The prisoners mostly used Morse code. However, she would applaud inmates if they sang a song which infuriated the guards. All they wanted was the systemic breaking of the prisoners under maddening silence. They definitely did not appreciate prisoners building solidarity among themselves by a group song, punctuated with clapping. Darya talked with herself or her mother who was not there. She would also repeat her entire interrogation sessions. M.A. said that when Darya was brought back to Evin, she was completely mad, skinny, and with bulging eyes (cited in Sadr & Amin, 2012, [Page number is not provided to protect Darya's anonymity]). Many thought that Darya must have been raped, although there is no way to confirm or deny this assumption. She would perform the scenes that might have happened to her, such as unwanted sexual contact. We interpret these attempts as a way for Darya to communicate her pain and resistance to her comrades. Darya used dramaturgy as a rhetorical device aligned to madness. Dramaturgy aided Daria to go wholesomely non-normative in telling others what happened to her. This was much superior to a normative, and yet seemingly acceptable, statement. Darya appeared to have lost her hold on the here and now. Her face was just bones. M.A. pointed out that everyone realized that Darya "was not feeling well" (i.e., *hālesh khōb nabōd*), since her body language told her story loud and clear. M.A. said in her testimony that she was afraid of Darya. She avoided her. She believed that the reason they brought Darya back to the ward was to show what the ultimate resistance would do to someone. Going mad was a warning sign. She testified that looking at Darya one could understand what can actually be done to someone's bodymind (cited in Sadr & Amin, 2012).

F.A. was placed next to Darya in Gohardasht prison. F.A. said in a radio interview that Darya was taken out of her cell and tortured for a while (we refrain from giving reference to the interview to protect Darya's identity). When she was brought back, according to her cellmates, "she had lost her psychological balance" (i.e., *ta'ādol e ravāniash rā az dast dāde bood*). This expression is used in Persian/Farsi to indicate the onset of "madness." She sang the famous socialist anthem, the "*L'Internationale*" in French in her cell, which has been a standard of the socialist movement since the late nineteenth century. It appears, as though, she was using her voice to resist the maddening silence and to declare herself alive. As soon as the guards heard her, she was taken away for more torture and interrogation. They brought her back after a few days, while she was in a very bad psychological state. She screamed constantly and protested her living conditions. One day, Darya, persistently washing herself, had left the water tap on in her cell, and water had leaked outside, which enraged the guards, and they beat her up. They turned off the main water pipe to her cell, so she did not have access to water any longer. F.A. and her mates learned by experience that this type of obsession with cleaning and compulsion to self-wash characterized women prisoners who had been sexually abused by the guards. They had basically observed that usually inmates who were raped felt "unclean" and "dirty" and washed themselves compulsively. Darya was doing the same after coming back from an interrogation session. This is another indication that any behavior perceived as mad cannot be understood outside its social and historical context. We are never mad inside our bodies alone. Rather, we are perceived as mad by others who interpret our behavior as madness. In this case, if we contextualize Darya's "obsessive-compulsive" behavior, which resulted in over-cleaning, we would start to see it as a response to the embodied experience of violence and not a pathology.

Monireh Baradaran (2000) wrote in her memoir that Darya was incontinent and semi-conscious as a result of the [perhaps psychiatric] medication that she was given by the guards. Note that medicating Darya was perhaps causing Darya's mental health and physical issues rather than "fixing" them. One of the prisoners who happened to be a nurse frequently asked the guards to take Darya to the prison clinic, but they took her to the Gohardasht's notorious solitary, instead, and kept her there for 2.5 years. She never got back to her former self. Monireh reports that she saw Darya years later in Ghezel Hesar prison where she thought she had become "better" with the help of the pills. According to Monireh, Darya was an extraordinary learner and teacher. On the days that she felt well, she would study or teach French to others. Those who had seen her there remembered that the guards constantly beat Darya because they thought that you could treat "mental illness" by physical beatings. In the contexts of total isolation, psychiatric symptoms emerge, even in prisoners with no history of mental health issues. There is extensive literature documenting the horrific effects of solitary on prisoners (see Kupers, 1999, 2006; Rhodes, 2004).

Raindrop in a Swamp

Darya was released in 1988. She went to Europe, where she joined Amnesty International and also helped asylum seekers with their cases. According to a friend, who saw her in Europe after her release, Darya found the outside world very different from how she had left it. Her socialist dreams had turned into, what Esmaeil Khoei called, "a raindrop that fell into the swamp." It seemed that what Darya and her comrades had stood for was not the people's main concern any longer. People were living their lives as if the IRI was a legitimate state with popular support. The internal contradictions, inherent to every revolution and massive social change, were too much to handle for almost all political prisoners who were finally released. Few months after her release, unfortunately, she passed away or committed suicide. There are several contradictory stories about how she died or, perhaps, ended her life.

Darya's story brings into sharp relief the non-linear workings of TDM. For one thing, TDM is not a sequential and linear narrative; and for another, it can transpire without externally verifiable traces. For example, Darya's story may invoke hitherto dormant sentiments that someone may have for his/her community which went unnoticed so far.

Madness Is Intersectional, Political, and Historical

Resistance is intersectional and multi-modal emerging from multiple narrative universes. It is also collective, coming from different conceptions of madness (e.g., madness as response-ability, madness as an alternative way of being in the world). Intersectionality also involves mutual learning and pedagogy among and within different groups of marginalized people in and beyond carceral spaces. And an act of witnessing is always intersectional depending on where we draw our lenses from. Consider the following ways in which madness has been stigmatized and institutionally framed.

History shows that mad people have been imprisoned for their non-normative behavior (read also self-expression, sexuality, gender, race, ethnicity, and class). Political dissidents have been imprisoned for their resistance against the hegemony of state power. They are both about social and political control of the "undesirable," so power can remain in the hands of the elite and ruling class who decide who should be swept away to the corners of disciplining institutions and who is allowed to be included in the society.

Many nation-states incarcerate their political prisoners in psychiatric institutions by implicitly conflating political resistance with psychological "disorders." This is to say that the authoritarian states (e.g., former Soviet Union, China) or even liberal states (e.g., the United States) engage in incarcerating their political dissidents in psychiatric wards. People labeled mad also underwent incarceration, segregation, and torture by electroconvulsive therapy, lobotomy, and other inhumane techniques. Women who did not "obey" their husbands, slaves who ran away from the mandatory labor at the plantations, and gay people have historically been harmed and labeled by the psy apparatus as mad (Burstow, 2015). "'Psy' refers to the set of professionals who aim to intervene in and modify the behavior of others, including, but not limited to, psychiatrists, psychologists, psychotherapists, social workers, and guidance counselors, as well as paraprofessionals such as peer support workers" (Tam, 2012, p. 10).

Many communities remain historically harmed and subsequently receive a psychiatric label for their *responses* and reactions to the sources of their oppression. We have, for instance, "Long Term Historical Identity Based Trauma (community/group) [such as], the Native soul wound/colonization including residential school legacy, slavery, the historical subjugation of women, two thousand years of persecution of Jewry by Christianity, the burning of the witches, the use of gay men as 'faggots' or kindling in the burning of the witches)" (Burstow, 2015, p. 239). Another example is the Indigenous peoples forcibly held at the "Canton Asylum for Insane Indians," a federal psychiatric hospital in South Dakota, discussed in Susan Burch's book, *Committed*: *Remembering Native Kinship In and Beyond Institutions* (Burch, 2021).

As Eric Fabris (2011) has shown us, the first implication of receiving a psychiatric diagnosis is chemical or physical incarceration, if not both. We know from Foucault that incarceration in any sense, whether for racism, sexism, classism, sexuality, dissent, or madness, is political (Foucault, 1964). It has long been argued by anti-psychiatry and critical psychiatry theorists that madness or "mental illness" is a myth and a socio-political construct with no biological and/or biomedical evidence to prove its existence. Although psychiatry is an official branch of medicine and the only apparatus beside the criminal justice system that can imprison people against their will, many critics believe that there is no concrete evidence whatsoever to prove the existence of mental illness as a biological defect or malfunction (Szaz 1987; Burstow, 2015; Whitaker, 2002; Foucault, 1964).

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Using TDM, committed to intersectionality, materiality, and transnationality, we examined a historical case of a mad revolutionary woman from Iran at the intersections of torture, ideology, theocracy, patriarchy, state, gender, and disability. Drawing on the DHM, we defetishized Darya's disability (madness) by demonstrating how madness and "sanity" can be socially organized and imposed by the violence of exploitative power relations (e.g., theocracy and patriarchy). We theorized disability (madness) as a historical materialist category and provided a dialectical reading of how the bodymind of political prisoners is rendered disabled by the state even as the disabled bodymind serves as an act of resistance against the state power. As racialized activists-scholars from the global south, we struggled in this chapter to re-articulate disabled-dissident subject's response-abilities in the form of madness.

Bearing witness to the story of Darya, and others whose names we do not even know, the ways in which we understand disability/madness should be rethought. We should not pretend we already know what madness is/means after bearing witness to what happened to the Iranian dissidents who were forced to stare at Gorgon (Agamben, 2002), lost their capacity to speak, and ended their own lives. It is at this incomprehensible moment that we want to push the field to think anew and go beyond irresistible orientalist and neo-conservative traditions of reducing women from the global south to exotic objects, submissive wives, or cultural selves floating non-relationally in a socio-historical vacuum. The figure of a mad woman, a political dissident fighting an entire state apparatus with her bodymind, is what shatters the diverging boundaries of previously held ideas. Our project here was to go beyond the rights-bearing subject and to push the onto-epistemological boundaries of the humanities and social sciences to understand political violence as it injures the bodymind and as the bodymind responds to this power by dissent.

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Monstrous Intersectionalities

34

Jasper J. Verlinden

> *"Thus, as soon as genre announces itself, one must respect a norm, one must not cross a line of demarcation, one must not risk impurity, anomaly, or monstrosity."*
> *(Derrida, "The Law of Genre" 57)*
> *"[. . .] and I will devour any*
> *attempt to subdue me with monstrous animality."*
> *(Cyrée Jarelle Johnson, "false sonnet embroidered w/ four loko empties")*
> *"It is time for a feminism of the monstrous."*
> *(Rev. Elena Rose Vera, a.k.a. Little Light, "the seam of skin and scales")*

Contents

Abstract

The relationship between disability and trans studies and activism is fraught, not only because of transphobia and ableism in the respective movements but because of a diagnostic parceling up of bodies and identities into discrete categories that go back to the nineteenth century. This chapter uses the figure of the monster, one of the oldest representations of embodied difference, to challenge the "categorical exclusions" (Hong, 2002) between trans and disability. Delving into the history of monstrosity, the chapter not only advocates for an intersectional perspective that

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traces the converging lines of disablement, normative gendering, and racialization in constructions of the monstrous but also argues for the employment of the monster as itself an intersectional analytic. In the final section, the chapter turns to the case of Layleen Polanco, a Dominican trans woman who died in 2019 while incarcerated at the Rikers Island prison complex in New York in order to highlight the real material consequences of these discourses for racialized, disabled, and gender nonconforming bodies.

Introduction

"The monster's body is a cultural body" (Cohen, 1996, p. 4). This is the first of the seven titular theses that Jeffrey Cohen presents in the introductory chapter to his edited volume, *Monster Theory: Reading Culture*, a text that has become standard in the field of monster studies. It is a statement that is both true and misleading. The monster is a construct to be sure. As well as a projection of the fears, desires, and anxieties of a certain culture. And when Cohen goes on to say that "the monstrous body is *pure culture*," (ibid., my emphasis) I take it to mean that there is no materiality that can be thought of as monstrous outside of its designation as such through a specific cultural lens. Yet, Cohen's language mirrors the Western Enlightenment language of Frankensteinian creation: it is Culture (read *logos*) that is the implied subject of his passive sentence structures and which "creates" and "gives life" to the monster. For Cohen, not only the concept of the monster, but its very embodiment is a creation born out of the cultural unconscious of the dominant order as the uncanny Other which exists only in function of its creator.[1] While compelling, this suggests that the monstrous body is merely ideological, that it exists only in the realm of signification (as a metaphor or signifier), and that if the veil of ideology were to be lifted, we would find nothing underneath. Or else that what is underneath that veil is rendered harmless and fully knowable within an already existing (or newly emerging) epistemological framework. While the first of these options belies the embodied materiality, the fleshy substance of those beings that have come to be read as monstrous, the second suggests a progress narrative in which monstrosity is just an effect of an ignorant superstition on nonconforming, unruly bodies that would be remediated with increased knowledge about the bodies in question.

The monster is possibly the oldest representation of embodied difference. As such, it has served since ancient times as a warning not to stray off the beaten path, a sentiment that is plainly encapsulated in the well-known phrase "Here be dragons," referring to the drawings of dragons and other mythical monsters that inhabited the margins of medieval maps to mark unknown or dangerous

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[1] Although Cohen describes the monster as being *given* "an uncanny independence," he also states that "the monster exists *only* to be read" (p. 4, my emphasis).

territories.[2] "Monster," however, does not only describe those fantastical beings that fill up our screens in the forms of zombies, aliens, or artificial intelligence gone haywire. Monstrosity has always and continues to be ascribed to human bodies, or rather bodies that are regarded as *in*human or less than human. Employing an intersectional perspective to monstrosity, specifically one that is mindful of the analytics generated by disability, trans, and critical race studies, it becomes possible to see how "monster" is what Sara Ahmed has called a "sticky" signifier, a signifier that sticks to other signs/signifiers as well as bodies and objects "as an effect of a history of articulation, which allows the sign to accumulate value" (2004, p. 92). Hence, my concern is not only to see how the concept of monstrosity "sticks" to some bodies more than others, e.g., trans bodies, disabled bodies, racialized bodies, but also how the stickiness of monstrosity collects, as it were, associations with disability, gender (nonconformity), and race, resulting in a sticky web of signification. "[W]ords stick," Ahmed explains (though in addition to words, I would also add here concepts, objects, and feelings), "because they become attached through particular affects" (ibid., p. 60). Once they stick, they may be invoked "through past forms of association" without being spoken (ibid., p. 92). Following this idea of stickiness, this chapter will not only provide an intersectional perspective on monstrosity but will also aim to use the monster as itself an intersectional analytic – a sticky concept that has accumulated value through past associations with various forms of nonnormative embodiment. In doing so, I hope to avoid either rendering the monstrous body into a mere sign without a referent or casting it as a dehumanized subject in need of rehabilitation. The chapter will first delve into the usage and history of monstrosity in relation to transness and disability before turning to the case of Layleen Polanco, a Dominican trans woman who died in 2019 while incarcerated at the Rikers Island prison complex in New York. While the first sections aim to ground the analysis within a wider and longer framework of disciplinary and historical discourses, the final section intends to highlight the real material consequences of these discourses for racialized, disabled, and gender nonconforming bodies.

Cripping Trans and Transing Disability

Both disability and trans discourses have had a long engagement with the concept of monstrosity, though very rarely are they brought in relation to each other. In 1993, at a conference titled "Rage Across the Disciplines" held at California State University, San Marcos, Susan Stryker gave a performance in which she invokes the figure of the monster from Mary Shelley's novel and claims it as a powerful site of identification. The piece, titled "My Words to Victor Frankenstein Above the Village of Chamounix: Performing Transgender Rage," would, in its published form, become one of the seminal

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[2] While the phrase only very rarely appeared on medieval maps, it was later used to retroactively describe the practice. According to Chet Van Duzer, there are only two known appearances of the phrase "hic sunt dracones" on medieval maps and globes, though similar phrases were used referring to lions, griffins, and "men with huge ears," among other monstrosities Van Duzer, 2014, p. 311.

texts of trans(gender) studies, launching it as an academic discourse at the same time as it established the monster as one of its most persistently reoccurring tropes. In disability studies, monstrosity is discussed less as a site of identification.[3] Rather, it is more present in historical accounts of disability that trace the construction of specifically congenital disabilities to older discourses of monstrous births – from the portents of antiquity to the pathologized objects of teratology, the study of congenital anomalies in plants and animals. The monster in these accounts is a precursor to the so-called *freak of nature*. Yet, although the language of deformity abounds in both Shelley's novel as well as Stryker's invocation of it, Stryker does not incorporate disability into her analysis and nor do the majority of trans studies scholars writing about monstrosity. Conversely, trans theorizations of monstrosity are rarely cited in disability studies and neither is transness included in its accounts of monstrous embodiment, even in discussions of the freak show for which performances of gender nonconformity were a staple.[4]

This mutual exclusivity is indicative of the historically fraught relationship between the two discourses which a number of scholars have attributed to the presence of ableism and cisnormativity in trans and disability studies and activism respectively (cf. Clare, 2013; Kafer, 2013; Puar, 2014; Baril, 2015; Timmons, 2020). When trans and disability are brought together, it is usually, as Jasbir Puar points out, "only in terms of the intersectional 'trans-disabled subject' or the 'disabled trans subject'" (Puar, 2014, p. 78). This privileging of the intersectional subject, however, as Puar goes on to argue, can actually distract from establishing broader alliances, as "[s]uch approaches" often provide "a gestural intersectionality that can perform a citational practice of alliance without actually doing intersectional research or analyses" (ibid.). When not centered on the "intersectional subject," scholarship on the intersections between trans and disability tends to focus on the commonalities between the struggles of the two movements and the possible alliances between trans and disability politics and activism (cf. Mog & Swarr, 2008; Timmons, 2020). Alternatively, trans and disability analytics are combined to develop a queer-feminist critique of normative bodily paradigms (cf. Hall, 2009; Wilkerson, 2012). Some of the most critical perspectives on the "categorical exclusions" (Hong, 2002) of trans and disability can be found in US legal scholarship that questions the political, ideological, and moral underpinnings for the legal exclusion of "transvestism, transsexualism" and "gender identity disorders" from coverage under the Americans with Disabilities Act (ADA), among "other sexual disorders not resulting from physical impairments" such as pedophilia, exhibitionism, and voyeurism (42 U.S.C. §1221; cf. Hiegel, 1994; Hong, 2002; Strassburger, 2012; Barry, 2013). While these scholars provide important work in challenging the legal grounds for these exclusions, and thus also the legal definition of disability, their main objective is the subsumption of transsexualism under the legal category of disability, as well as civil

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[3] This does not mean that the monster does not function as a site of identification for disabled people at all. In her oft-cited essay "On Being a Cripple," for example, Nancy Mairs invokes an identification with Shakespeare's Caliban, "a most scurvy monster" (see Mairs, 1986, p. 15). While Riva Lehrer, in her boldly titled memoir, *Golem Girl* (2020), cites a host of monsters as points of identification, from Frankenstein to werewolves and spider women.

[4] Two notable exceptions to this overwhelming trend are Clare (2015) (first published in 1999) and Sears (2015).

rights protection for transgender persons under the ADA. Rarely are the broader categories of trans and disability themselves questioned: they are simply assumed and assumed to be distinct.

Indeed, the separation between "trans" and "disabled" is so stark that even scholars whose aim is to bring the two together still end up emphasizing their distinctness. Alexandre Baril, for example, argues that transness should be recognized as debility, which, citing Julie Livingston, he defines as "the impairment, lack or loss of certain bodily abilities"[5] and aims to deconstruct "the borders between" transness and disability (Baril, 2015, pp. 61, 64; cf. Livingston, 2005). At the same time, he clarifies that he is "not saying that trans and disabled realities are identical or interchangeable," and that "despite significant similarities and intersections, trans and disabled people's experiences are different" (ibid., p. 63), reconsolidating them as discrete categories (cf. also Mog & Swarr, 2008; Clare, 2013, 2015). However, I would contend that given the variety of identities and forms of embodiment that are gathered under the umbrellas of "trans" and "disability," one could argue that there are more differences between various experiences of disability or transness than between transness and disability themselves. My aim here is not to do away with difference altogether, but to ask why certain forms of difference are considered to be distinct while others are grouped together as denoting common experiences. Thus, rather than regarding this discursive split as primarily a matter of interpersonal ethics – of unconscious ableist and cisnormative biases that when addressed can be overcome, enabling a more inclusive politics – I want to emphasize the historical and structural conditions that occasioned this separation to begin with. This I hope to do by looking at historical accounts of monstrosity, with specific focus on gender nonconformity.

"All Base, All Barbarous": Genealogies of the Monstrous

The word "monster" is generally traced to two etymological roots: the Latin verbs *monere*, meaning to warn, and *monstrare*, meaning to show. As such, the monster functions as a sign that always signals something outside of itself: a warning of impending disaster or a sign of God's will. As Rosemarie Garland-Thomson writes in her introduction to her edited volume *Freakery: Cultural Spectacles of the Extraordinary Body*, monstrous bodies are "always an interpretive occasion. [. . .] Never simply itself, the exceptional body betokens something else, becomes revelatory" (Garland-

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[5] Baril draws not only on the work of Livingston, but also of Jasbir Puar to develop his concept of debility (see especially Puar 2009). Whereas debility and its relation to disability are points of contention within the wider framework of disability studies, this particular debate goes beyond the scope of this chapter. Baril doesn't offer a clear delineation between debility and disability. His argument is rather that the medicolegal management of transness as well as the social expectations of gender have mentally and physically debilitating effects (sometimes purposefully created) that lead to forms of impairment that are not readily recognized as disability. One striking example is compulsory sterilization as a prerequisite for gender reassignment, which has only recently been abandoned in Germany, Belgium, and Sweden, but is still common practice in many other national contexts (see also Verlinden, 2012).

Thomson, 1996, p. 1, 3). As the now familiar narrative goes, from antiquity until roughly the Enlightenment era, monsters were seen as portents and prodigies, marvels and wonders. They included mythical beings, often human–animal hybrids, as well as people we would now call disabled, racialized, and those who were considered sexually ambiguous. The common denominator was that the monster crossed and thus challenged boundaries: between human and animal, self and other, male and female, etc. In the seventeenth and eighteenth centuries, however, the monster comes increasingly under the purview of science, turning an ever more medicalized gaze unto monstrous bodies, i.e., bodies marked by difference. No longer prodigious, these bodies now become "freaks of nature" in need of correction (cf. Garland-Thomson, 1996).

In her recent book-length study on Renaissance representations of disability, however, Elizabeth Bearden takes to task both scholars writing about monstrosity in the Renaissance period as well as disability studies scholars for taking for granted the "grand narratives of disability's past" (largely influenced by Foucault), "from supernatural miracle, to natural marvel, to medical anomaly" (Bearden, 2019, p. 7). While she commends the work that has been done by scholars like Lennard J. Davis and Garland-Thomson on the "nineteenth-century advent of lexicalization, institutionalization, and social and statistical norming of disability," she argues that there is a romanticized misconception of medieval and early modern conceptions of disability as somehow free from "norming influence[s]" (ibid.). Similarly, in 1996 already, Stephen Pender also questioned this narrative of clear historical development, which he believed did not "take account of the complex, often conflictual status of the monstrous in the early modern period," as well as the distinctions "between the portentous and the merely anomalous" (Pender, 1996, p. 145). As he points out, it is difficult to gain a clear picture of the discourses around monstrosity in the early modern period as the evidence is spread out among a large variety of texts that do not necessarily conform to one particular discourse or genre (ibid., p. 146). What is clear, according to Pender, is that "the meaning of monsters was renegotiated throughout the early modern period" (ibid.).

Following these challenges made to the discourse, I want to question another distinction that structures disability studies' narrative of the history of the monstrous. In her 2009 book, *Staring: How We Look*, Garland-Thomson states: "Authentic monsters are born, never made" (Garland-Thomson, 2009, p. 178). In her elaboration, it becomes clear that authentic monsters are people born with a (highly visible) congenital disability, while inauthentic monsters are "high-tech, pop-culture monsters such as King Kong, Yeti, and Mummies" (ibid.). What is left out from this binary are those bodies that are considered monstrous but can neither be subsumed under the category of congenitally disabled, nor are they merely fantastical. Disability studies' emphasis on monstrous *births* effectively cuts out transness from its conception of monstrosity. After all, as Stryker writes in her "Words to Victor Frankenstein": "The transsexual body is an unnatural body. It is the product of medical science. It is a technological construction. It is flesh torn apart and sewn together again in a shape other than that in which it was born" (Stryker, 1994, p. 238). While there is a very clear line of interest in pre- and early modern writings on monstrous births, I would suggest that this represents only a subsection of a broader understanding of monstrosity.

Perhaps one of the reasons for this overemphasis is that monstrous births constitute events that are spectacularized through the discourses around them. As Kevin

Staggs writes: "Stories of bewildering and horrific births were a popular form of news in England and Wales over the course of the sixteenth and seventeenth centuries. They combined sensational detail of malformed bodies and horrified and distressed families with dire warnings of the need for all to repent" (Stagg, 2006, p. 21). On the other hand, other forms of deformity that are either acquired or discovered at a later stage are less spectacular and thus seem more quotidian. According to Katherine Schaap Williams, this distinction gained momentum in disability studies with Lennard J. Davis influential 2002 book, *Bending Over Backwards: Disability, Dismodernism and Other Difficult Positions*, in which he writes that "under the previous discursive grid, anomalous, strange births were distinguished from disabilities that were acquired" and "unless the deformity is wondrous, it is ignored or erased" (Davis, 2002, p. 53, see also Williams, 2015). One could argue, however, that this erasure is more an effect of the twentieth- and twenty-first-century reception of these discourses rather than an actual fact of medieval and early modern culture. One figure that to me challenges this clear distinction between the born and the made is the hermaphrodite.[6]

While the hermaphrodite, who is generally acknowledged as one of the prime historical examples of monstrous embodiment, is often at least citationally included in disability studies' discussions of monstrous births, it is assumed in those accounts that hermaphroditism is simply the precursor of what we now call intersex. But historical constructions of the hermaphrodite do not map neatly onto modern-day intersex bodies, nor can nature and culture – the born and the made – be so clearly separated in these historical depictions. Firstly, even if one understands the hermaphrodite as a monster that is born rather than made, they often did not fall into the spectacularized category of monstrous births since the condition was often only discovered later in life, as is attested by the numerous court cases surrounding the subject in early modern society. Secondly, what constituted the categories of the born and the made were not always clear-cut and distinct. One of the most famous monsters of Renaissance Europe, the so-called "Monster of Ravenna," was not only depicted as having wings instead of arms, a horn on its head, the foot of a griffon, and other elements that mark it as a human–animal hybrid, but it was also usually represented as having both a penis and breasts. Yet rather than read these depictions through a naturalistic lens that interprets the sexual features in light of a particular diagnosis of intersex or DSD, it is important to acknowledge the symbolic nature of the imagery. What we see is not a literal depiction of an intersex condition (indeed, most of the images of the Ravenna monster depict it as an infant or a child, too young for actual breast development), but a symbolic representation of sexual intermediacy that found expression not only through an admixture of genitals or even secondary sex characteristics, but also included attributes that we would now firmly place in the socially constructed realm of gender.

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[6] When I use the term "hermaphrodite," I refer to a historical construction, not to individual people unless they identify as such. As will be shown below, I am here not interested in the reality of the hermaphroditic body in order to identify current diagnoses of intersex or DSD (Disorders of Sex Development), but rather in the ways in which these bodies were constructed and discussed in historical texts.

In their discussion of early modern French discourses on hermaphroditism, Lorraine Daston and Katherine Park note an increased interest in and emerging anxiety about hermaphroditism in late sixteenth- and early seventeenth-century France, which they attribute to its increased association with transvestism and sodomy, especially between women. While medieval authors from time to time also used hermaphroditism to refer to sodomy, such as Dante who described the sins of male sodomites as "hermaphroditic" (cited in Daston & Park, 1995, p. 424), according to Daston and Park, "medical literature that was produced after about 1550 not only devoted intense attention to hermaphroditism but also associated it to a far greater extent with the sexually, theologically, and morally charged issues of sodomy, transvestism, and sexual transformation" (ibid., p. 423). The French surgeon Ambroise Paré, for example, has a chapter on hermaphroditism in his *On Monsters and Prodigies* (1573), an often-cited text in disability studies accounts of the history of monstrosity, in which he includes "a long discussion of sex between women" (ibid., p. 423) and "lesbian anatomy" (ibid., p. 424), followed by a chapter in which he discusses "a series of what he terms 'memorable stories of certain women who degenerated into men'" (ibid., p. 423). Significantly, although Paré expanded these sections for the second edition, he was forced to remove them from subsequent editions because of protests from the medical establishment who, according to Paré, deemed it "unfit to be read, recited, and heard by Christians" (quoted in Daston & Park, 1995, p. 424, cf. also FN 14 p. 433).

In a different national context, an example of the relation between transvestism and hermaphroditism can be found in the anonymous *Hic Mulier; or, The Man-Woman* pamphlet that circulated in England in 1620 and in which the author suggests that, as Ruth Gilbert explains, "by affecting masculine gender attributes cross-dressed women, 'these new Hermaphrodites,' transformed themselves into *monstrous hybrids* who distorted their 'womanly' essence" (Gilbert, 2002, p. 84, my emphasis). In fact, multiple times throughout the text, the author describes these cross-dressing practices as monstrous deformities and links them to other forms of monstrosity – describing them as "giantlike," "Mearemaids, or rather Meare-Monsters," something that "Goblins themselves start at," and even meteors – as well as to other forms of sexual transgression such as prostitution, adultery, and bestiality (cf. *Hic Mulier* 1973). As the author also suggests, it is these acts of sexual transgression, likely already performed on the part of the mother, that engendered these "unnatural conceptions" in the first place (ibid.), further complicating the distinction between the born and the made: although the act of cross-dressing is acknowledged as a practice, the monstrous cross-dressers themselves were pushed back into a framework of heredity and blood ("from any purer blood would have issued a purer birth").[7] While it is not to be excluded that the invocation of the monstrous in this text is more metaphorical, it is clear that monstrosity is used to indicate hybridity, excess, and the threatening crossing of boundaries.

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[7] The mother carried a lot of responsibility in early modern conceptions of monstrosity as the mother was often held responsible for the occurrence of a monstrous birth, not only due to her sexual practices, but also her anatomy (in the Aristotelian tradition), and even her imagination as is discussed by Huet 1993 (cf. also Canguilhem, 2008, pp. 138–139).

Daston and Park relate this newfound obsession with hermaphroditism to the revival of the Hippocratic tradition which viewed hermaphrodites as being of intermediate sex, placing them on a spectrum with masculine women and feminine men (cf. Daston & Park, 1995, p. 423). This view diverged from the Aristotelian tradition which had reigned for a longer time and which viewed hermaphrodism not primarily as a matter of sexuality, but of the doubling of body parts, thus relating it more to those forms of monstrosity that manifested through excess limbs or the conjoining of twins (ibid., p. 421). The Hippocratic idea of sexual intermediacy – combined with a male anxiety regarding "female pretensions to masculine status and prerogatives" (ibid., p. 431) – threatened the strictly sexually bifurcated legal and natural order of early modern European society and gave the hermaphrodite a distinct aura of illicit sexuality. As a consequence, hermaphrodites were no longer trusted to judge for themselves which sex predominated, as was mostly the case in earlier periods: as Daston and Park contend, they were not free to choose as Foucault claimed,[8] rather they were trusted to interpret the signs provided by nature, which as the hermaphrodite came of age presented itself mostly through (hetero)sexual attraction. The newfound ambiguity around sexual intermediacy, however, led to an increased reliance on medical authority to uncover nature's intentions. Moreover, since as Daston and Park further point out, "nature" included "not only procreative capability, but also the other related signs, such as activity and passivity, [. . .] character and conduct" (ibid., p. 428) such as "bold speech" and "impudent action" (*Hic Mulier* np), a careful reading of the body was necessary to uncover and distinguish natural inclination from simulation. Thus, the boundaries between what constituted monstrous sexual behavior which had to be eradicated, i.e., sodomy and transvestism (those who committed sodomy risked the death penalty), and monstrous embodiment which needed to be managed, i.e., hermaphroditism or sexual transformation, became more fraught and in need of stricter delineation. So, although there is a distinction between the born and the made in the sense of nature vs. artifice, in the case of hermaphroditism and other sexual transgressions, both are considered monstrous, while the made in this context, as the gender panic[9] that arose from the examples above shows, carries the added stigma of immorality.

A closer look at the *Hic Mulier* pamphlet reveals that there are multiple kinds of panic at play. Aside from the invocation of monstrosity and deformity, one particular paragraph of the text stands out for its description of the practice of transvestism as "all base, all barbarous." It is "barbarous, in that it is exorbitant from Nature and an Antithesis to kinde." The author continues:

> What can bee more barbarous, then with the glosse of mumming Art, to disguise the beauty of their creations? To mould their bodies to every deformed fashion: their tongues to vile and horrible profanations, and their hands to ruffianly and uncivill actions? [. . .] If this bee not

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[8] Cf. Foucault 1980, p viii. For another critique of Foucault's discussion of hermaphroditism in relation to the transing of the Frankensteinian monster trope, see Koch-Rein (2019).

[9] Though she writes about a different time period and context, my use of "panic" is inspired by Gayle Salamon's *The Life and Death of Latisha King: A Critical Phenomenology of Transphobia* (2018).

> barbarous, make the rude Scithian, the untamed Moore, the naked Indian, or the wilde Irish, Lords and Rulers of well governed Cities.

While there is also no unified discourse on barbarism at this time – its meanings ranging from simply foreign or having different customs, to savage, wild, and cruel – it almost always connotes being other, uncivilized, and non-Christian, a discourse that played a large part in the justification of colonialism.[10] In this text, the author clearly links barbarism to racialized others who threaten to conquer the city. As Jean Howard writes in her discussion of this passage: "In a stunning revelation of a racial and national chauvinism, the aspiration of women beyond their place is associated with the monstrous notion of the black in rulership over the white, the Irish over the English" (Howard, 1988, p. 425). The description of the "deformed fashion" that the women mold their bodies to also echoes the descriptions found in early colonial travel literature of the time, of the indigenous peoples of the Americas or Africa who also "molded" their bodies to "deformed fashions." One example that circulated at the time is *Nova Francia, or The description of that part of New France which is one continent with Virginia* written by the French author Marc Lescarbot and published in English in 1609, in which he describes how "with these large nostrils, the Brasilians are accustomed to make themselues yet more deformed by Art, making great holes in their cheekes, and vnder the lower lippe, for to put therein greene stones and of other colours, of the bignesse of a tester: so that those stones being taken away, it is a hideous thing to see those people" (Lescarbot, 1609, p. 180).

A later but more well-known example of these dynamics is seventeenth-century physician John Bulwer, whose *Anthropometamorphosis* (1650), which Kevin Stagg describes as "a survey of ethnic monstrosity" (Stagg, 2006, p. 19), provides a kind of enthnographic account of the cosmetic practices of a number of foreign places, from European nations like France, Germany, and Portugal (among others) to more remote places in Asia, Africa, and the Americas, concluding his rather encyclopedic volume with a chapter on the fashion of the English. These cosmetic practices, which he gleaned from scientific writings and travel accounts, included those of the kind as found in Lescarbot's description of the people from Brazil above, but curiously also a lot of physiognomic traits, such as the shape of the head or nose, as well as some of the monstrous races which before were included in natural histories, such as the "Nation of Cynocephali, or Men with Dogs-Heads," which he says are "reported to be *Negroes* inhabiting a Mountaine neere the River *Indus*" (Bulwer, 1653, p. 19, emphasis in original) and the "Acephali, or a headlesse Nation" (ibid., p. 20), which he places in

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[10] An example from roughly the same period is from *A reporte of the kingdome of Congo, a region of Africa, and of the Countries that border rounde the same* by Philippo Pigafetta who used the writings of Odoardo Lopes from Portugal. The text was translated from the Italian by Abraham Hartwell and printed in London in 1597. Hartwell writes in his introduction: "I thought good thus to make it knowen to my countreymen of England, to the end it might be a president for such valiant English, as do earnestly thirst and desire to atchieve the conquest of rude and barbarous Nations, that they doo not attempt those actions for commodity of Gold and Silver, and for other transitorie or worldly respectes, but that they woulde first seeke the Kingdome of God, & the saluation of many thousand soules, which the common enemie of mankinde still detayneth in ignorance" (Hartwell, 1597, np; cf. also Hall, 1995, pp. 40–44 for further discussion of Hartwell).

diverse areas in Asia and Africa. Other perhaps surprising inclusions in a book on customs are "a Nation of Hermaphrodites," which he places in Florida and Virginia (ibid., p. 386) and men with enlarged breasts which he locates in Egypt (ibid., p. 317). What is most surprising perhaps to current readers is that he describes all these as resulting from artificial practices.[11] As is already apparent from a glance at the title page, Bulwer's concern in this book is not only the distinction between nature and culture or, in his words, artifice, but mainly the transformation of "Man" through culture:

> Anthropometamorphosis: Man Transform'd: or, THE ARTIFICIALL CHANGLING Historically presented, In the mad and cruell Gallantry, foolish Bravery, ridiculous Beauty, filthy Finenesse, and loathsome Loveliness of most NATIONS, fashioning and altering their Bodies from the mould intended by NATURE; With Figures of those Transfigurations. To which artificiall and affected Deformations are added, all the Native and Nationall Monstrosities that have appeared to disfigure the Humane Fabrick. With a Vindication of the Regular Beauty and Honesty of NATURE. And an Appendix of the Pedigree of the ENGLISH GALLANT. (Bulwer 1653, title page)

Contrary to writers of the later Enlightenment period for whom nature was the province of the "natives" of colonized territories, Bulwer locates culture as foreign, while nature, which he equates with "regular beauty and honesty," he sees as the purview of white English men (as long as they did not engage in sodomy or other gender nonconforming practices, as shown below). Although there is a certain admiration and perhaps even desire in his description of these artificial practices ("ridiculous beauty," "filthy finesse," "loathsome loveliness"), they clearly have the power to "disfigure the Humane Fabrick." Like in the *Hic Mulier* pamphlet, cultural practices become inheritable traits. It is culture then which is monstrous above all.

Again, "unnatural" gender practices and race come together and conspire to produce monstrous deformities, from the "Sodomiticall Boyes" of Persia "who make an unrighteous use of the *Rectum Intestinum*, to the foule shame and dishonour of their Bodies. Which Contagion hath spread both into the East and West *Indies*"; to "young men in womens apparrell smooth and effeminately decked" (Bulwer, 1653, p. 413); women with facial hair: "Woman by Nature is smooth and delicate; and if she have many haires she is a Monster" (ibid., p. 215); Patagonians, "a Race of Giants, in the fortieth Degree of the South Pole," who "trusse their Genitall members so, as it is hidden within their body, which is a transgression against the morall Law of Nature, established in our members" (ibid., p. 353); to eunuchs and the "Semi-Eunuchs" of the "Cape of good-Hope" (ibid., p. 354) which is followed by an account of castration (ibid., p. 355) and then cannibalism (ibid., p. 356), the ultimate violation of the boundaries between self and other which here comes through as not only a racialized but also a sexualized practice. It is especially in the last chapter on "the English Gallant," however, that the anxiety around deformity comes out most of all. This chapter functions as a warning to the English that the adoption of foreign "artificiall and affected Deformations" would "disfigure" the English

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[11] This tendency can already be seen in Lescarbot's account as well, as he states that "the Brasilians are borne as faire as the common sort of men, but coming out of the wombe, they are made deformed in squizing of their nose" (Lescarbot, 1609, p. 179). Bulwer, however, takes this idea much further.

"Nation" (ibid., p. 536; note that "nation" is here used more in the sense of an ethnic group than a political entity). Throughout the book, the images show Bulwer's fascination with an exotic racialized otherness. Although he includes images of Europeans as well, the vast majority are of individuals from Asia, Africa, and notably many of various indigenous peoples of the Americas. In the final chapter, he juxtaposes the images of foreign and racialized deformities with images of the English customs that he believes approximate them. This proximity creates an urgent address to the English to forego these abominable practices in order to – in a kind of past echo of nineteenth-century eugenics discourses – prevent the degeneration of the English race.

Linking back to the *Hic Mulier* pamphlet, transvestism, and other gender nonconforming practices thus becomes a nexus for multiple types of anxiety. Gender panic is fueled, in the first instance, by an insistent threat of deformation, the early modern conception of which does not fully overlap with our current categories of impairment or disability. As David M. Turner notes: "While the stigma of deformity derives from the appearance of bodies, modern definitions of disability focus more on the functions of bodies and their relationship to their social and physical environment" (Turner, 2006, p. 2). As such, deformity is primarily an aesthetic deviation from the norm.[12] But the pervasive anxiety surrounding deformity found in these early modern texts suggests a deeper anxiety around bodily integrity (that relates to a mental and spiritual integrity as well) that I would call a disability panic. Both of these then give rise to a third panic, a racial panic. These texts provide a kind of layering of social anxieties that consolidate and take shape in the figure of the monster. Thus, what the monster shows is that one kind of panic tends to invite another. Gender nonconformity, for example, is not only an affront to the laws of gender but also an affront to bodily integrity, as well as an affront to racial integrity.[13]

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[12] Interestingly, John Bulwer was also known for his sympathetic treatises on deafness and the possibility of education for people with hearing disabilities. He is also considered to be the father of English sign language. This suggests that while deafness was seen as a disability in the sense of a restriction on full participation in society, Bulwer did not regard it as a deformity as it was not a violation of the aesthetic norm.

[13] The question of race in the early modern period is a complex and highly debated topic. It has been commonplace for many years for scholars to claim that race as we understand it today is a nineteenth-century invention and that to apply that lens to earlier periods can only be anachronistic. More recent scholarship, however, takes a more nuanced view on the subject. Ania Loomba and Jonathan Burton's introduction to their documentary reader, *Race in Early Modern England* (2007), is especially helpful here, so I quote it at some length: "The appropriateness of 'race' or 'racism,' 'xenophobia,' 'ethnicity,' or even 'nation' in describing community identities in early modern Europe has been much debated. Some of these words were coined later, and others, such as 'race,' did not necessarily convey the same meanings they do now. [...] [E]ven when modern-day meanings of words such as 'nation' or 'race' emerged in the early modern period, older or competing meanings retained a place alongside or in competition with them. But surely this complexity does not suggest that it is anachronistic to study race in the early modern period. After all, 'race' is, even today, a confusing word that does not carry a precise set of meanings, but becomes shorthand for various combinations of ethnic, geographic, cultural, class, and religious differences. [...] As is the case in the modern world, when we examine early modern notions of racial difference we must consider not only those divisions of humanity that were putatively based on distinctive combinations of physical traits and transmitted through a line of descent, but also the

What these anxieties further show is that there was a mutability to the body that had to be contained. Gender nonconforming and other subversive cultural practices were endowed with a kind of monstrous agency that threatened the social and natural order. In the eighteenth and nineteenth centuries, scientific discourses became more invested in differentiating and classifying monstrosity into discrete categories of abnormality (cf. Foucault, 2003). Disability, race, and gender/sexuality all become discrete categories that also gain ever more internal divisions. Hermaphroditism, for example, became first separated into the medicalized identity categories of "the homosexual" and "the (congenital) hermaphrodite," and later, in the twentieth century, into the three categories that we are now familiar with: homosexuality, trans, and intersex. This separation has conspired to diffuse the radical potential of the monster and render the individual and separate manifestations of it subject to either pity or annihilation. Medico-legal discourses have worked to distinguish forms of embodied difference and separate them into distinct areas of expertise that bring them under the purview of different institutional authorities. However, as many scholars working on the intersections of race, gender, and disability, especially in a historical perspective, have shown,[14] the specters of association never disappeared. On the one hand, this compartmentalization has worked to foreclose any meaningful alliance between marginalized communities. At the same time, it belies and thus obfuscates the discursive coconstitution of difference that undergirds these discourses themselves.

Toward a Feminism of the Monstrous

On June 17, 2021, following the death of EJ Boykin, a Black trans man who was killed in Virginia 3 days earlier, The Human Rights Campaign (HRC), a US-based organization dedicated to LGBTQ rights, reported that "[t]he level of fatal violence [they have] recorded this year is higher than [they have] ever seen" (Lhant, 2021). This pronouncement came less than 7 months after they had issued their 2020 report on "fatal violence against transgender and gender non-conforming people in the United States" (published annually in November to mark the Transgender Day of Remembrance), in which they reported a record number of deaths, prompting them to declare an "epidemic of violence" (2020). While the HRC listed 44 cases of fatal violence against trans and gender nonconforming people in the United States in 2020 (HRC, 2021), the Transgender Murder Monitoring Project (TMM) of the organization Transgender Europe (TGEU) reported "a total of 350 trans and gender-diverse

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eclectic range of cultural differences that are used to explain, manage, or reorganize relations of power" (Loomba & Burton, 2007, p. 2). Other landmark studies on racial difference in early modern England include Hall (1995) and Wheeler (2000).

[14] To name just a few pertinent examples: for a transhistorical account of the intersections of race and disability, cf. Erevelles, 2011; for a transhistorical and intersectional perspective on trans and race, cf. Snorton, 2017; on race and (homo)sexuality in the nineteenth century, cf. Somerville, 2000; on trans, race, and disability in nineteenth century San Francisco, cf. Sears, 2015.

people registered murdered between 1 October 2019 and 30 September 2020" worldwide (TGEU, 2020). Both note a general increase in reported cases. In reality, the numbers are likely to be much higher, as the HRC explains, "data collection is often incomplete or unreliable [. . .], [s]ome victims' deaths may go unreported, while others may not be identified as transgender or gender non-conforming" (HRC, 2020). The lists also do not reflect the number of hate crimes that did not result in fatality or deaths that can be linked to mental or physical health issues that resulted from discriminatory practices (e.g. lack of access to healthcare, excessive policing, bullying, etc.). Similarly, in their 2019 report on hate crimes, the FBI noted a marked rise in disability hate crimes. And the Disability Day of Mourning project tracks and commemorates the people with disabilities who were specifically murdered by a family member or caretaker, while "The Ruderman White Paper on Media Coverage of Police Use of Force and Disability," published in 2016, states that "[d]isabled individuals make up a third to half of all people killed by law enforcement officers," a fact that is often left out of media coverage, emphasizing that "[d]isability intersects with other factors such as race, class, gender, and sexuality, to magnify degrees of marginalization and increase the risk of violence" (Perry & Carter-Long, 2016, p. 1). This ritualistic invocation of statistics has become an integral part of lives that are under constant threat of violence in a society that has marked them out for disposal, reminding us of Audre Lorde's recitation: "We were never meant to survive."[15]

What this brief look at the statistics also suggests, however, is how the separation of modes of oppression into different axes that only intersect in particular bodies – e.g., the "trans-disabled subject" (Puar, 2014, p. 78) or the "black.female.queer" (Holland, 2012, p. 12) – but otherwise remain essentially distinct, renders invisible the larger structural mechanisms that manage these categories of difference in relation to each other.[16] Ironically, this invisibilization of the structural frameworks also renders illegible the particular situationality of these often-invoked intersectional subjects themselves. In this final section, I want to close by drawing attention to a recent case that illustrates the need for a deeper and more thorough structural and historical engagement with the intersections of trans, disability and race. On June 7, 2019, Layleen Cubilette-Polanco, a 27-year-old Black Dominican trans woman from New York, and a member of the House of Xtravaganza, died at Rikers Island while she was being held in a "restrictive housing unit," a form of near-solitary confinement reserved for purposes of punitive segregation where she was placed after allegedly assaulting another prisoner. In their "Report of the Investigation into the Death in Custody of Layleen Polanco" (2020), the Bronx County District Attorney's Office (DAO) describes Polanco's death as follows:

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[15] From Lorde's 1978 poem, "A Litany for Survival."

[16] For further critique of the use of intersectionality only in terms of the representation of intersectional identities and embodiment, see Haschemi Yekani (2022).

> On June 7, 2019, she was found unresponsive inside of her cell by Correction Officers and was later pronounced dead on scene. The Office of the Chief Medical Examiner found that the cause of Ms. Polanco's death was "sudden unexpected death in epilepsy due to mutation in her CACNA1H gene," ruling the manner of her death as natural. Ms. Polanco suffered from a seizure disorder and had other medical issues prior to June 7, 2019. (Clark, 2020, p. 2)

Although the New York City Department of Corrections (DOC) states in its directives that "persons with 'serious mental or physical disabilities or conditions' are barred from being placed [in punitive segregation]" (Clark, 2020, p. 16) and the staff at Rikers Island was not only aware of Polanco's medical status, but also noted "radical changes in [her] behavior" that they felt "should be brought to the attention of the Mental Health Staff" (ibid., p. 6), the DAO concluded that the threshold for criminal charges in this case was not met, meaning that no one would be prosecuted or held liable for Polanco's death.

The reasoning for this conclusion hinges on the fact that the DOC does not "define what serious physical and mental condition is for the purposes of Punitive Segregation" (Clark, 2020, p. 24) and that none of the staff could have known that Polanco would suffer life-threatening seizures during her time in restrictive housing (even though she had already had several seizures during her time at Rikers). They also reason that "it cannot be established that Ms. Polanco would have survived even if she was housed in general population" (ibid., p. 21). Furthermore, although, as the report states, the DOC requires corrections officers to monitor "signs of life" – for example, "the rise and fall of the chest [. . .], snoring, or some body movement" – in any incarcerated person confined to restrictive housing "at least once every half-hour on each tour of duty" (ibid., p. 15), Polanco had been unresponsive for at least 2 h before they called in medical help. The DAO finally concluded that:

> There is no evidence that they acted with the level of carelessness required by the statute. They periodically checked in on Ms. Polanco and reportedly saw her lying in bed – thinking nothing was wrong, none of them entered the cell. They complied with their requirement to make their rounds. (ibid., pp. 22–23)

It is noteworthy that in its conclusion, the report emphasizes that: "the purview of this Office is not to determine whether the decision to place Ms. Polanco into Punitive Segregation [. . .] while she was suffering from a documented seizure disorder, was wrong; rather, the purview of this Office is to determine whether that decision rose to the level of criminal behavior" (ibid., p. 24). In other words, while the staff at Rikers might have been wrong or made mistakes, they could not be held criminally liable for those mistakes. In the official DAO record, Layleen Polanco thus emerges as the tragic victim of a medical condition, "a sudden unexpected death in epilepsy," resulting from her own body's unruly production of a mutant gene, rendering her death natural and ultimately not reasonably preventable, as the reason for her being in punitive segregation is also attributed to her own unruly behavior, which was described by the DOC as "highly assaultive" (ibid., p. 5).

Another perspective on the case emerged with a later report issued by the Board of Corrections (BOC) which has independent oversight over the correctional facilitates under its jurisdiction. In this report, the Deputy General Counsel, Kate McMahon, finds several infractions on the part of correctional officers as well as a number of systemic failures. First of all, there is the failure on the part of correctional officers to "round every 15 min [not 30 as stated in the DAO report!] as required by DOC policy [. . .], leaving Ms. Polanco unobserved by DOC staff for stretches of 57 min, 47 min, and 41 min during the period between when she was last confirmed alive and when the medical emergency was declared" (McMahon, 2020, p. 11). What is even more significant, however, is that correctional officers were apparently "confused as to what DOC policy requires in terms of rounding frequency" (ibid.), they were "never informed that Ms. Polanco had a seizure disorder, and nothing in the DOC housing area records that BOC reviewed referenced Ms. Polanco's propensity for seizures" (ibid., p. 8), and they were not "adequately trained to conduct quality visual observations and confirm signs of life" (ibid., p. 12). Additionally, the report specifies that the "radical changes in behavior" reported by staff, which occurred the day after she was placed in confinement, included "expressing a desire to commit suicide and/or attempting suicide;" "having hallucinations/delusions (seeing objects or hearing voices that do not exist);" "showing poor personal hygiene or appearance, doesn't shave wash or change clothes, etc.;" "being alarmed (frightened) or in a state of panic;" and "inmate randomly crying, shouting" (ibid., p. 4). But although a psychiatrist from the Correctional Health Services (CHS) "verbally stated that due to [her] medical history as it pertains to seizure disorder that he would not be able to authorized [sic] a cell housing placement for inmate [Polanco]" (ibid., p. 6), the report finds there was "undue pressure" on the part of the DOC (ibid., p. 11) to place Polanco in Restrictive Housing, evidenced by an email from the Tour Commander stating that "We tried very hard to get Inmate [Polanco] cleared [for segregation] but [Mental Health] just won't clear her. We are in the process of generating [Protective Custody] paperwork for [her]" (ibid., p. 6). As the report states, this insistence to segregate Polanco was because of the "DOC's determination not to house a transgender woman in general population housing areas for cisgender women" (ibid., p. 11). In fact, it is common practice in many prisons to place trans inmates in solitary or near-solitary confinement, supposedly for their own protection, as indicated by the Tour Commander's instrumentalization of "Protective Custody" procedures. A further indictment to Rikers came in the form of a video released by Polanco's family which showed correctional officers laughing and talking for 2 min while apparently calling out to her instead of going inside her cell to check on her well-being, especially since she had already been unresponsive for a considerable amount of time. The family filed a wrongful death lawsuit against the city of New York and 25 anonymous members or Rikers' staff which was settled in the amount of $5.9 million.

In order to more fully understand the circumstances that led to her death, however, we have to look at the broader structural convergences. We have to ask ourselves what the conditions were that led to Polanco's incarceration in the first place and how her Black, trans, disabled, and criminalized body rendered her illegible as a person deserving of care. It is important to note that during the time of her death, Layleen Polanco was being held at Rikers on bail, meaning that she had not yet been convicted of any crime. In April 2019, Layleen Polanco was arrested for allegedly assaulting a cab driver, but as the prosecution was unable to secure any deposition to support their case, the court had reduced bail, initially set at $500 to one dollar. However, Polanco still had an outstanding bench warrant (an arrest warrant that is given out due to nonappearance in court) for earlier charges of misdemeanor prostitution and low-level drug possession. Rosa Goldensohn and Savannah Jacobson reporting for *The City* state that, according to the Manhattan District Attorney's Office, "[a]n undercover cop arrested Polanco in August 2017 for allegedly agreeing to engage in oral sex for money and having what police called a crack pipe in her pocket" (2019, np). Following this earlier arrest, Polanco was mandated to appear in Manhattan's Human trafficking Intervention Court, a court that refers those arrested on prostitution charges and whom it deems victims of human trafficking to mandatory counseling. Or in the words of New York State Chief Judge Jonathan Lippman: "the New York State Court System will [. . .] identify trafficking victims, refer them to services, and restore them to law-abiding lives" (Center for Court Innovation, 2013). Polanco's failure to appear in this Intervention Court is what led to the outstanding bench warrant and an additional bail amount of $500, resulting in a total amount of $501 which she was unable to pay. However, since Polanco engaged in sex work of her own volition, it is not clear how a court that intervenes into sex trafficking would help her. On the contrary, "restoring" her to a "law-abiding life" would have effectively deprived her of her livelihood.

It is also important to view Layleen Polanco's arrest and death in relation to larger structures that conspire to police bodies that are marked by race, gender nonconformity, and disability. These include laws that prohibit "loitering with the intent of prostitution," which have come to be known as the "walking while trans ban" as they have been used to disproportionately target trans women, especially trans women of color. "Crimes against nature' laws, also known as antisodomy laws, which, in spite of the Supreme Court decision in the case of *Lawrence v Texas* in 2003 which deemed these laws unconstitutional, have still not been repealed in a number of states, especially in the South. While antisodomy laws, which criminalize not only consensual anal intercourse, but also oral sex, have historically been enforced almost exclusively to police consensual same-sex relations, they have been increasingly used to target trans women, again especially trans women of color. Another context that played into Polanco's arrest is the ongoing War on Drugs, which, as Michelle Alexander and other critical race scholars have shown, is used to disproportionately target Black and Latinx people (the NYPD's reference to Polanco's alleged "crack pipe" is instructive here; cf. Alexander, 2010). Furthermore, we need to take into account the relations between disability and incarceration. As Liat Ben-Moshe argues in her recent book, *Decarcerating Disability: Deinstitutionalization and Prison Abolition* (2020):

> [D]isability is central to mass incarceration and decarceration in the United States. This is true in terms of both the disabling nature of incarceration in prisons and the pervasiveness of incarceration (whether in so-called therapeutic facilities like psych hospitals or punitive ones

> like jails) characterizing the lives of many disabled people whether in so-called therapeutic facilities like psych hospitals or punitive ones like jails [. . .]. (Ben-Moshe, 2020, p. 1)

Not only had Layleen Polanco been shuttled between psychiatric facilities and the prison several times (she was sent to Bellevue Hospital before being placed at Rikers and during her time at Rikers, she was sent to Elmhurst Hospital where she spent 8 days in the Psychiatric Prison Ward), it should not be overlooked that her repeated encounters with police and the insistent threat of violence and incarceration leveled at her racialized trans body severely affected her mental health. Additionally, people who are stigmatized for what is seen as a "disturbed" mental state ("erratic," "randomly crying, shouting," "assaultive") or for involuntary bodily movements (e.g., seizures) are often considered to be inherently dangerous and in need of segregation. Finally, the explicit exclusion of trans from the ADA has led to trans people being rejected from health coverage, not only for trans-related medical needs, but also for completely unrelated health concerns. And while trans people continue to be marked as "mentally ill," very real trans-specific mental and physical health concerns are not recognized at all, and they are also not protected under the ADA with regard to employment or housing discrimination.

The monster is a figure that instills fear. Fear of contamination, of a loss of self, a loss of bodily integrity. Monstrous figures, after all, manifest a kind of conspicuous visibility that resists rehabilitation within the normative category of the human. It is a body that needs to be contained and rendered harmless – dis-abled – either through management (biopolitics) or annihilation (necropolitics). While the history of monstrosity might seem a far-removed issue for most, it still plays a huge and often devastating role in the lives and deaths of those whose complex embodiment and positionality resist neat categorization and render them suspect in a multiplicity of contexts. Layleen Polanco, as well as many other boundary-crossing beings that emerge from the historical archive, still represents a threat because of the monstrous agency that they embody. While agency usually describes an ability to act, to be an agent, in the social or symbolic order, this presupposes that your actions are legible to the dominant order. Monstrous agency, I would suggest, is a kind of agency that is dangerous or threatening to the social order because it subverts its categories, crosses its boundaries, and disrupts the "law of genre" that prohibits hybridization (cf. Derrida, 1980). As such, it is a form of power or capacity that is not necessarily intelligible in the social order. Rather, it is a form of power that comes from a place of abjection.[17] It is the appropriation and thus subversion of identities and practices that were meant to contain rather than enable. It is to derive power from a source not intended for you. As such, it is a power that marks one off as dangerous and in need of containment or elimination.

What I hope to have shown with both the historical examples as well as with the case of Layleen Polanco is that the strict separation of identity categories and the

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[17] My use of abjection is informed by the work of Julia Kristeva, specifically her seminal text, *Powers of Horror: An Essay on Abjection* (1980; trans. 1982).

policing of their borders only works to mask their ontological interdependencies, by which I mean that they never exist in and of themselves but always only in relation. My aim in this piece is then not only to offer an intersectional perspective of the monster, but to advocate for an understanding of intersectionality that is itself monstrous: an intersectionality that radically questions the boundaries of the categories it operates with, that questions the category of the human itself and resists the need to rehabilitate monstrous subjects within that category.

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Black-Abundance, Fat-Revolt, and Crip-Desire: Intersectionality as Interference in the Life and Death of Rohan Garfield Salmon

Fady Shanouda and Terri-Lynn Langdon

Contents

Abstract

This chapter is an examination of the life and death of Mr. Rohan Garfield Salmon, an evicted resident of a long-term care home in Ontario, Canada. It will be shown that Rohan's experiences both demonstrate the healthcare system's abject failures as well as the agentic capacity of difference. Rohan's case, more than highlighting the deplorable state of care in the nursing home-industrial-complex, suggests that critical analyses of intersecting social categories must consider the emergence of those categories in intra-actions – in emergence with other humans and nonhumans. The authors argue that Rohan simultaneously experienced constricting forces from dominant cultural understandings of fatness, blackness, and disability and also produced equally disrupting and interfering forces – reimagining the capacities and desires of his bodymind. In particular, the

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chapter will highlight how *fat/black/disability-becomings* created certain conditions that successfully prevented the state from exercising its force for nearly 2 years. The authors invite scholars to consider how such analyses, that take into consideration the material things, can open up ways of understanding the different capacities of individuals too often already marked as disposable.

Keywords

Fat black disability studies · Interference · Material semiotics · Long-term care · Resistance · Police · State violence

Introduction

In the Summer of 2017, Rohan Garfield Salmon was served an eviction notice from Sunrise Senior Living for failing to pay rental arrears in the amount of $18,000 (Zarzour, 2019). In the subsequent 3-year legal battle between Sunrise Senior Living, the Newmarket Enforcement Office, and Rohan, the rapacious corporations, and impermissible violations of the nursing home-industrial-complex (Tremain, 2021) would come into full view. Rohan died in 2019, only a few days after learning that a provincial Court had sided with Sunrise, and that he would be evicted. The appalling gaps in long-term care in Canada are longstanding (Estabrooks et al., 2020) and were made more glaring during the COVID-19 global pandemic, where disabled communities witnessed the devastating loss of life in care homes across the country. Rohan's life ended before COVID-19 was rampant in assisted living spaces. Still, the same negligence and ill-care that caused the over 15,000 deaths during the pandemic in Canada are apparent in Rohan's case as contributing factors to his eviction and untimely death (Inter Pares, 2021). Undeniably, Rohan's life and death add to the justifiable outpouring of criticism against this system. The chapter's focus is to capture the deeply flawed state of disability care in Canada pre-pandemic and to add to the chorus of calls to abolish different forms of institutionalization and incarceration (Linton, 2021; Fritsch and Shanouda, 2022).

In this chapter, the authors examine the intricate relationship between oppressive forces, and consider the different ways disability, race, and size were entangled in the life and death of Rohan Salmon. It will be shown that Rohan's experiences both demonstrate the healthcare system's abject failures as well as the agentic capacity of difference. Rohan's case, more than highlighting the deplorable state of care in the nursing home-industrial-complex, suggests that critical analyses of intersecting social categories must consider the emergence of those categories in intra-actions – in emergence with other humans and nonhumans. It is a reminder that relations of power are not determinant but can re-form and are in constant becomings (Grosz, 2011).

In reflecting on Rohan's life, the authors argue that he simultaneously experienced constricting forces from dominant cultural understandings of fatness, blackness, and disability and, in relation to other humans and materials things, produced equally disrupting and interfering forces – reimagining the capacities and desires of his bodymind. In particular, the chapter will highlight how *fat/black/disability-becomings* created certain conditions that successfully prevented the state from exercising its force for nearly 2 years. The authors invite scholars to consider how such analyses, that take into consideration the material things, can open up ways of understanding the different capacities of individuals too often already marked as disposable. Examining relations of power with material things in mind can extend analyses beyond predeterminant stories of subjugation, and begin to include experiences of and capacities for resistance, agency, and change – becomings too often ignored.

The authors started researching and writing about Rohan after he died, and therefore never had a chance to meet and interview him, as they would have wished. Therefore, the analysis relies on those who wrote about Rohan in court documents, Sheriff's statements, and news media. The authors also interviewed Kim Zarzour, a reporter who wrote several articles on Rohan's case, and his lawyer, Melissa Miller, who represented him until his death. Both Kim and Melissa expressed deep admiration for Rohan and remarked on how psychologically taxing and affecting reporting and representing him had been on their personal and professional lives.

The chapter has four sections. First, a discussion of Rohan's legal case and the changes in management at his residence that precipitated the rental increases and subsequent eviction. Next, an introduction to an intersectionality-as-interference (Barad, 2007; Geerts and van der Turin, 2013) approach and the significance of analyzing Rohan's experiences through a onto-epistemological lens. To demonstrate Rohan's agentic capacity, the analysis focuses on his social classifications in relation to three material objects and describes how these emergences (between Rohan, the material object, and staff at Sunrise) made and unmade differences. This will show that contrary to the dominant cultural understanding of fat/black/crip-ness as dying/death/dead, Rohan expressed life. In the final section, alternatives to long-term care are described. Together, these sections demonstrate that in the legal and healthcare systems, Rohan was experiencing the collective force of dominant intersectional cultural perceptions of fatness, blackness, and disability as disposable, although he expressed a desire for life and living. Focusing on what residents *do,* rather than what it means, might illuminate their capacities for life, and change social and cultural understandings of what it means to live in assisted and long-term care spaces.

Mr. Rohan Garfield Salmon: September 27, 1968–January 30, 2020

Rohan immigrated to Canada from Jamaica in 1977 (Fanfair, 2018). He attended Carleton University and received his Master's from the University of Ottawa. In 2002, he was an ESL teacher on a day trip with his students when their vehicle overturned and crashed (Fanfair, 2018). One of the students died, and Rohan acquired a spinal cord injury from the chest down. Following the crash, he was in recovery at a hospital for almost a year and spent several months on a rehabilitation ward. In 2004, Sunrise Senior Living, a retirement home in Richmond Hill, Ontario, Canada, that provides assisted living and memory care services, offered Rohan a basic package of 1 hour of care a day, supplemented by 3 or more hours of care from his insurance. Sunrise Senior Living is part of a much larger care system in Canada comprised of long-term care, nursing homes, groups homes, and other supportive-living centers. There are approximately 200,000 disabled people living in these contemporary institutions, 23,650 under the age of 65, and 230 under the age of 18 (Statistics Canada, 2021).

Sunrise's initial care package would have included a lift for transfers, personal support workers for his personal care and hygiene needs, and assistance with all household tasks. In 2015, under new management, Sunrise reassessed Rohan's level of care and ultimately determined that his needs had increased. In Ontario, care homes are allowed to increase rental fees once a year only at a specific rate. Still, they can increase the costs of care services and meals as much as they need (Zarzour, 2018) – a rule that can put residents in a place of financial precarity and uncertainty. They can also change the rental costs with a new tenant – making quick turnovers an essential part of their business plan.

However, Rohan insisted that his care needs had not changed since his accident. His doctors came to the same conclusion (Fanfair, 2018). Sunrise disagreed and insisted he take on the additional costs for the care plan they were implementing. At the same time, Sunrise also alleged that Rohan was in arrears for a rental increase that took effect in late 2014 (Zarzour, 2019). In total, Sunrise Senior Living demanded Rohan pay $28,358.46 in rental arrears and the additional costs of care or find a new place to live (Zarzour, 2018). Rohan's living options were always limited because of the scarcity of bariatric equipment to support his size and living needs in the Ontario healthcare system (see Shanouda, forthcoming-1). Rohan later learned that Sunrise had notified him of the rental increases in writing but had placed the letter in a mailbox that he never used because it was not accessible to him. In the past, the Sunrise director had delivered similar news to him in person.

Rohan called a friend who helped him hire a lawyer. They decided to settle, and Rohan sent Sunrise a cheque for the initial cost of arrears of $14,700. Sunrise informed him that they would not be accepting his payment and that they would be evicting him. Rohan would enter several legal challenges over the next couple of years and ultimately die weeks before the final written decision concerning his eviction was published. Speaking with his lawyer, Melissa, the authors learned that Rohan was informed of the oral decision to press on with eviction days before he died. Melissa said, "He cried, and it was very difficult. He went into shock."

Rohan's legal case is compelling, and its many different decisions are worthy of further study. However, the chapter's focus is on the tensions that arose between Sunrise, the Court, and the Sheriff's Office. These three entities shifted blame and responsibility for Rohan's care and housing back and forth and kept him persistently in limbo for the duration of the legal proceedings. This is not a unique part of his case, but given his care – and not just living accommodations – were provided by Sunrise, Rohan was facing a diminishing level of support. Sunrise's retaliatory actions included changes to his laundry schedule (that would ultimately result in him lying in dirty sheets), reduced hours for daily bathing (that would increase the chances of a urinary tract infection), and theft of his personal belongings. These experiences were never part of the court proceedings. Still, they demonstrate the harm and consequences he experienced upon entering into legal battle with the corporation that housed him and provided his care.

After Sunrise refused to accept Rohan's cheque for the lapsed rent, it became the Sheriff's office's responsibility to evict Rohan. According to the Residential Tenancies Act, one of the statutory duties of the provincial Sheriff's office is to physically evict tenants when there is a legal order due to non-payment of rent. However, in Rohan's case, the Sheriff's Office refused to comply with the eviction order "due to the unique circumstances" of health and safety in this case (*Sunrise North Senior Living Ltd. v. The Sheriff (Regional Municipality of York)*, 2020). The Sheriff also noted that although it is customary to involve the police in eviction orders where a tenant is legally required to leave, their primary role, in this case, would be to keep the peace.

In response to the Sheriff's decision, Sunrise applied to the Newmarket Court Enforcement Office – which oversees enforcement of three main areas: (1) subpoena documents and enforcement, (2) orders to appear in court, and (3) eviction orders (Sheriff's Office, 2020). This office determined that Rohan could not be evicted from his residence since "there was no safe place for Rohan to be moved in light of his underlying physical challenges and associated daily care needs." Sunrise responded by applying to the Divisional Court for a *mandamus order* against the Sheriff. As the Latin term implies, this results in a mandatory order from the court to a government agency to meet its obligations and legal duties. The Divisional Court granted the mandamus order without specifying how the Sheriff should carry it out. Ultimately, the Sheriff's failure to comply would constitute contempt of court.

Sunrise sought clarity from the Superior Court in Newmarket which upheld the eviction order and determined that Rohan did have a place to go. However, no evidence of such a place outside of long-term care ever seemed to materialize. In the legal decision, the Superior Court states,

> With absolutely no disrespect to Mr. Salmon, and while I have sympathy for the position in which he finds himself, having no right to remain at Sunrise and nowhere to go (he says), he is, in effect, a homeless paraplegic. I am confident that in Ontario in 2018 (and now 2019), there is some place, or places, to which the sheriff may safely take such a person, upon carrying out an eviction order. It is, in my view, the public duty of the sheriff to determine what that place or places are, and to carry out the eviction (*Sunrise North Senior Living Ltd. v. The Sheriff (Regional Municipality of York)*, 2020).

The judge's expectation of an accommodating place for Rohan relied on inappropriate options, including other retirement homes that did not have enough space to accommodate Rohan (such as proper bariatric lifts, wider doors, staff that could lift and bath him) or accommodate his belongings, long-term care homes, which he refused to consent to, and even short or long-term stays in a hospital. The judge determined that these were reasonable alternatives. The judge also determined that the Sherriff's office was the expert in this situation and could reasonably find accommodations for Rohan – when all evidence points to the contrary. The Court granted the mandamus order and directed the Sheriff to enforce the eviction order and pay Sunrise costs of $20,000. Rohan died in the hospital from septic shock, precipitated by a UTI infection, before the Sheriff had a chance to evict him.

The changes to Rohan's rent and the suggestion that his care needs were increasing came after new management took over at Sunrise Senior Living in 2015. These changes were likely consequences of restructuring that followed the purchase of Sunrise Senior Living by Revera Inc. and Health Care REIT (Revera Inc, 2014). Revera is a Canadian/multinational corporation that owns, invests in, or manages over 500 properties in Canada, the USA, and the UK and claims to support over 55,000 seniors/residents. In 2006, the Public Sector Pension Investment Board (PSP), a federal Crown corporation charged with investing funds for the pension plans of the federal public service, the Canadian Forces, the Royal Canadian Mounted Police, and the Reserve Force, bought Revera (Ontario Health Coalition, 2020; Tasker, 2020). In 2019, before the COVID-19 pandemic, Revera faced 85 lawsuits from individuals across Canada who were seeking damages between $150 and 175 million (Hoye, 2019). Since COVID-19, the company is facing an additional $120 million class-action lawsuit for the loss of life, neglect, lack of testing, and improper sanitation experienced by residents during the pandemic. The estimated size of the class is over 10,000 plaintiffs (Guly, 2020). This is just one of many lawsuits against long-term care providers across Canada. There are continued calls by the public sector union Public Service Alliance of Canada to divest from Revera (Kennedy, 2020), and a recent report on the crisis in long-term care settings outlines both the legal and operational risks of continued investment in for-profit long-term care spaces (Uni Global Union, 2020). The PSP has yet to divest.

Therefore, Rohan was living in a senior residence owned by the pension fund for Canadian police and military. Sunrise was managed and operated independently of the PSP; however, the timing of his reassessment and rental increases with Revera's takeover is too convenient. These two actions have allowed Sunrise Senior Living to place Rohan's room and care at current market value – likely doubling their income in the process, according to Rohan's lawyer (Melissa Miller, 2021, "personal communications"; Fanfair, 2018).

Rohan made his case public. He was a self-advocate and sought to bring public scrutiny to the conditions in the senior and long-term care settings in Ontario and Canada. He consulted with journalists; hired a lawyer; ensured that his story and the actions of Sunrise, Revera, and PSP would not go unnoticed. He also challenged the Court, the Sheriff, and Sunrise, often ignoring requests, partially complying with agreements between the parties – refusing to apply for long-term care and withdrawing his consent. It is the authors' assertion that Rohan was no longer willing to participate in a culture of compliance and was much more interested in a politics of resistance. He obfuscated the legal parameters to ensure he would stay at Sunrise. Kim and Melissa describe him as someone with their "heels dug in." His resistance mirrors the work and strength of disability activists in Canada and the USA fighting against assisted dying legislations as part of the Disability Filibuster (https://disabilityfilibuster.ca/) and other organizations, like Not Dead Yet (https://notdeadyet.org/). The authors argue that Rohan, like so many other self-advocates, simply refused to experience any further injustices. The following section will describe Rohan's relation to material things that made and unmade disability, race, and size and, contrary to the belief he was already dead, expressed his desire to live.

Intersectionality-as-Interference

The conditions of Rohan's eviction require an analysis that interrogates the systemic inequity he experienced. An intersectional analysis allows the authors to examine how racism, ableism, and fatphobia converge and entangle at these moments. It offers a way to understand how Rohan's experiences are a consequence of these various interlocking systems. Intersectionality is essential to the analysis because of its roots in black women's efforts to name oppressions and work toward transformational and structural change (Crenshaw, 1989). The authors are invested in the principal purpose of intersectionality – to interrogate the complex interconnections of forces of power and oppression that constitute a body disposable spatially, discursively, and materially. However, the chapter's aim is to learn what role Rohan played in relation to other human and nonhuman elements in the making and unmaking of difference in this situation. His bodymind differences mediated through the material objects around him prevented his eviction for a long time. Although he experienced significant pain and harm during this process, he was also resourceful and unyielding in his desire to stay put. This is a show of agency that must be a part of the analysis. The analysis suggests that the traditional ordering processes – the social script or status quo – were upended and thwarted in these moments of interference or disruption. As such, the authors explore Rohan's experience through patterns of interference to consider both power and structural inequity onto-epistemologically.

Interference (Barad, 2007) or intersectionality-as-interference (as described by Geerts and Van der Tuin (2013) is an examination of power structures that conceptualizes these as "the convergence of waves (light/sound/water), which results in patterns of intensification or higher intensity, while there are also places where the waves cancel each other or are weakened" (Verloo, 2009, p. 10 as cited in Geerts and Van der Tuin, 2013). Interference allows scholars to examine power structures without assuming that certain identities or relations of power are determinable. The chapter's focus is on examining power relations as patterns of interference or as crashes of waves without assuming a priori what can come of the interactions and emergencies.

This approach does not seek to abandon an intersectional lens. This would only reassert white European intellectuals over and above black women's scholarship and activism – a dynamic the authors are not interested in supporting (Pickens, 2019). Interference was developed by Haraway (1997), Barad (2007), Barad and DeKoven (2001), and Verloo (2006), but owes its intellectual rigor to black feminist scholars, authors, and activists including Crenshaw (1989), Collins (2000), Hooks (1984), and Butler (1993), who coined, developed, and evolved the concept of intersectionality to address systemic structures and see them change. By adding a lens of interference, the authors could examine "(power) relations differently, working with '[s]tructures [that] are constraining and enabling, not [just] determining'" (Barad & DeKoven, 2001: 99 as cited in Geerts & Van der Tuin, 2013, p. 176).

In thinking through Rohan's experience as intersectionality-as-interference, the authors also approached the research with Moser's (2006) work and writing in mind. Moser's (2006) analysis of the making and unmaking of differences in interactions with people and things, helped conceptualize Rohan's experiences in similar ways to consider disability, fatness, and blackness enacted materially and discursively. Moser (2006) refers to this approach as a material semiotics, which she states, "attends to. . .how particular practices carry and enact differences and also how that is enacted in and by the situation and all its elements without necessarily being intended, experiences, immediately obvious, or controlled by the human verbal participant" (p. 561). The intention is to think about how matter matters in these interactions and works to make and unmake differences outside of language.

Moser's approach to interference is also brought into discussion with Mollow's (2017) fat black disability studies – a transdisciplinary methodology developed to conceptualize the relationships between racism, ableism, and fatphobia. Mollow brings together critical race theory, fat studies, disability studies, and the Black Lives Matter movement to argue how systems of oppression are "weaponized" to further state-sanctioned violence. Although Mollow's focus is on anti-black state violence – specifically police murders of black people – she invites others to extend her analysis to other forms of anti-black state violence. The authors contend that senior living and long-term care spaces constitute forms of state-sanctioned violence against disabled, mad, and aging people – among others – as they are sites of incarceration and transinstitutionalization (see Haley & Jones, 2020). These are institutional sites that have transitioned through space, time, and elaborate social policy to continue to medically pathologize and express violence on marginalized communities, some of the most vulnerable in society. In Mollow (2017) she describes the healthcare system as part of state-sanctioned violence, especially against black women, like Barbara Dawson of Florida, who was denied care in a hospital and subsequently died in the hospital parking lot surrounded by police after she refused to leave.

The systemic murders of black adults and children by police are not comparable to the neglect of long-term care residents, but they are both products of state-sanctioned violence against bodymind differences (Ben-Moshe, 2020). The connection here is that the treatment of fat, black, disabled bodies are similar not because of their locations or sites of oppression or oppressors, but because they are conceptualized as already close to death.[1] Mollow (2017) argues that being so close to death makes "state-sanctioned violence...appear to have negligible effects" (pg.108). The authors contend that Rohan's bodymind differences put him close to death or already dead. Rohan felt this and said as much when he argued, "As time went by and I

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[1] See Razack, 2013, for a similar conceptualization of Indigenous people as already dead.

didn't die in the three to five years as most elderly residents, they [Sunrise] realized it was a bad deal [their initial rental and care offer] and they wanted to stick it to me. I have outlived anything they could have imagined, and they figured they have got to find a way to get me out" (Fanfair, 2018).

Sunrise was covert in its efforts to make its space unlivable for Rohan. They changed his care schedule; they ignored his personal choices, and they misplaced his belongings. Rather than focus on these as part of a larger scheme to push Rohan out, the authors argue that his capacity for life was contrary to everything expected of a fat, black, disabled man, all of which invited more scrutiny and objection.

The next sections focus on three material things that were not central in the legal proceedings or reporting on Rohan's legal case or life and death. The stories around these objects were relayed to the authors by Kim and Melissa – the reporter and Rohan's lawyer, respectively. In highlighting these objects and the stories around them in the analysis, it will be shown that Rohan was simultaneously becoming-fat/black/disabled and obstinate and difficult and already dead. As patterns of interference, these moments are acts of disruption and a desire for *difference*. They evoke a sense of who Rohan was and what he loved and how he sustained an agentic capacity in a space that had resolved to see him erased.

Food

In asking Melissa to recall moments of fatphobia and racism that she thinks Rohan might have experienced at Sunrise, she immediately brought up his preference for Jamaican food. As a Jamaican immigrant, it is reasonable that Rohan wants to eat food that he is familiar with, desires, enjoys, and views as healthy, nourishing, or indulgent. Additionally, according to this lawyer, Rohan wanted to eat Jamaican food to ensure he could maintain his cultural independence. However, Sunrise did not take this requirement seriously. According to Melissa, Sunrise staff described his food preferences as unreasonable and Rohan as intransigent.

Kelley (2016) argues, "The food we eat and its preparation define who we are culturally, socially, economically and politically" (p. 21). One could add that it also contributes to conceptions of health and wellness – and marks outliers in size as either eating too much and too little and of the wrong things. As a long-time fat person, Rohan would have been aware of the constant surveillance of the type and quantity of food he ate. Fat people experience a certain level of scrutiny when they shop for food or eat in public. Miller (2017) describes this as a part of the social contract between everyone else and the "Good Fatties" – to not rub fat people's perceived overindulgence in thin people's faces. The pressure to eat a salad (with dressing on the side, as Miller (2017) remarks) or only buy greens in the grocery store, is at times, overwhelming for fat folks. Performing as "Good Fatties" is how one can avoid stares or unwanted comments. In the end, it is a way to prevent forms of violence. Rohan would have been aware of this surveillance, and his requests for food – any type of food would have been remarked on and scrutinized. Rohan's requests for Jamaican food would have been perceived as less healthy or nutritious, and followed the over 100 years pseudo-scientific knowledge that marked the health disparities between White and Black people on racialized peoples' diets, according to Strings (2020). Requesting non-European food would have invited more attention to Rohan's size, bad eating habits, and inevitably become evidence of his lack of self-control, like so many others before him.

In requesting Jamaican food, Rohan was enacted not just as obese and unhealthy but also as intransigent, essentially meaning, difficult. Versions of this story are part of most black people's lives – the angry black women or men are familiar tropes (see Quaye, 2017). These ignore the histories of black people on Turtle Island[2] and turn justifiable rage against the constant threat of systemic violence into personal characteristics. Rohan thus becomes difficult through his requests to perform his blackness through food. He is difficult in his refusal not to eat more easily accessible, so-called "Canadian food." His stance against his ethnicity's erasure, and instead, its celebration, makes this a challenge to the status quo. More than just a microaggression, this defining of Rohan by Sunrise transforms him into an unreasonable individual. Rohan becomes the impossible client, the impractical, illogical, irrational individual. He becomes the *mad*, black man. Through this discursive and material entanglement, Rohan is made into a madman (Shanouda, forthcoming-2). This, according to Meerai et al. (2016) is an example of anti-black sanism, which "at its heart is the pathologization of simply being black" (p.19). The work on anti-black sanism exposes the ongoing systemic racism and dehumanization of black folks, as major factors in the development of distress in the black community as well as how black bodies are made not to matter in health, education, and legal systems (Meerai et al., 2016; Keating, 2016). Rohan understood this was taking place. He shared with a local news outlet that within the housing and care systems he was struggling with infantilization, and a continuing diminishing of his self-value.

Jamaican food made this situation unfold because it rejects the white culture that organizes the event-space[3] (Massumi, 2002) at Sunrise. Food within Sunrise is read "as a material object [that] has the capacity to act as an agential object. . ." (Kjær, 2017, p. 78). Food, in this sense, has a productive power to create an individual's social identity and embodied subjectivity. Rohan, through his desire and relationship to Jamaican food, was able to make present his fatness and blackness. Food made central and active his size and Jamaican ethnicity, forcing Sunrise and the staff to acknowledge those differences as significant. In the process of requesting Jamaican

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[2] Turtle Island refers to the continent more commonly known as North America. Turtle Island is the name given to this landmass by some of the Indigenous communities who have lived here since time immemorial.

[3] The "event-space" is a term used by Massumi (2002) to describe the "folding of dimensions of time into each other" (15). Puar (2012), borrows this term from Massumi to explain the possibilities of moving from analyses that take up intersectionality to those that think with Deleuze's concept of assemblage. The authors are thinking alongside these scholars in their work on shifting identity, subjugation, and/or privilege from any sense of interiority to one that explores how these experiences are relational and take place in the event-space between human, nonhumans, and more than human things.

food, Rohan accentuated the other food offerings at Sunrise – European or Americanized foods – white people's food that he was not interested in consuming. He unmade the white discursive and material logics that governed definitions of good food and healthy choices. Undoubtedly, food produced an "event-space" in-between Sunrise and Rohan that made and unmade the ways of thinking about food, race, and eating processes. His requests interfered with Sunrise's management style, and undoubtedly its conceptions of good, healthy food, and as a result, forced the corporation to adjust and shift, even for a short time. These were changes it was not interested in making and that certainly did not lower costs.

Cologne

Similarly, Melissa relayed to the authors that Rohan was an avid collector of expensive cologne. She described this as a sort of passion or hobby of Rohan's that he spent "serious money on." She remarked that he displayed these bottles all over his room at Sunrise and that she did not recognize many of the brands; his collection was sizable and unique. These bottles indeed held a certain level of significance for Rohan, not just because he spent time collecting them but that he also displayed them in his room. Unfortunately, when Rohan would leave Sunrise (often for health reasons), bottles from his collection were stolen. Additionally, according to Melissa, the Sunrise staff were mystified by Rohan's collection and perplexed as to why he would need cologne. They seemed to want to ask, "Who is Rohan trying to impress?"

The authors cannot say conclusively what collecting or applying cologne meant to Rohan. However, such actions surely enacted Rohan as a sexual and gendered person – interested in performing his sexuality. Perfumery, after all, is "rooted in the sexual drive," as Bain (1997) argues. Although interpreted through Melissa, the staff's remarks are like those disabled people and scholars have described in other places. Contemporary society has desexualized disabled people – rendered undesirable or worse, unworthy of love and relationships (Kattari, 2015; Liddiard, 2017; Shakespeare, 2000; Shildrick, 2007). Further, Sabrina Strings (2020) writes about how nineteenth-century racial categorization also "largely served to regulate who could enjoy romantic and sexual congress with whom." She also contends that this area of exclusion included fat bodies. Too often, disabled people are denied access to their sexual lives and made into sexless bodies, not only incapable of sexual expression, but themselves lacking sexual desire.[4]

Similarly, to his desire for Jamaican food, Rohan's choice to spend money and time on cologne was an expression of pleasure and joy. Expressing his sexuality, his pleasure in the little things not only made Rohan into a sexual person but also

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[4] Unlike previous discussions in disability studies scholarship, the authors*f* are not suggesting that Rohan was made asexual, as form of oppression, as that would deny the positive experiences of asexual disabled people (see Santinele Martino, 2017).

reaffirmed his interest in life and living. Through these material things, he becomes more than expected, thus rejecting the social script around the marker quadriplegic. This is contrary to the expectations. As Shackelford (2021) writes about fat, black bodies, they are expected to "Become no-thing." The expectations on Rohan's bodymind are that they, "Do not take space because it is not yours. . . Your existence does not afford you the right to be too much, too loud, too full, too human, too living, too free, too abundant. . ." (p. 253). Cologne enacted a sexualized intra-action that expressed an aliveness that was not just human or sexual but also destabilizing of traditional conceptions of disability. In the next section, Rohan's expression of life as disruptive, dangerous, and an act of resistance is further entangled with the other material things around him.

Mobility Devices

In this final example, the focus is on Rohan's deluxe rehab arm bike, custom-fitted wheelchair, and power chair. Together, they cost an estimated $65,000 and were incredibly important to Rohan (Fanfair, 2018). They not only allowed him to access the spaces and activities at Sunrise but made it possible for him to exercise and venture outside of Sunrise (Zarzour, 2018). Unfortunately, Rohan's equipment disappeared from his room 1 day. Rohan said,

> I was led to believe that it [the equipment] was in storage at Sunrise's Aurora location all this time. They told me they [the equipment] were safe and would be returned whenever I wanted them (Fanfair, 2018).

A week before his scheduled eviction, Sunrise informed him that the equipment was "gone" (Zarzour, 2018). Sunrise did not provide any additional information. As a show of good faith, they did offer Rohan $3500 in compensation. Rohan believes it was an inducement to keep quiet and leave without hassle. He said, "...this money [was offered] on condition that I never talk about the equipment again. I was also informed it was a one-time offer and if I accepted it, I would also have to move out..." (Fanfair, 2018). Sunrise claimed no responsibility for these missing/stolen items, much like the cologne, and denied any knowledge of how these large pieces of machinery were now "gone." Melissa intimated that Sunrise was unconcerned by Rohan's missing equipment, as it only made his living conditions more intolerable.

The significance of mobility devices for disabled people cannot be understated (Linton, 1998; Disability Rag, 1984). They produce access. They allow for the enactment of different capacities. They unmake definitions of disability as only ever limiting or confining. A wheelchair, therefore, is as much a tool to move around in as it is an instrument that expresses freedom, possibility, and a transgressive mode of embodiment and subjectivity. Fritsch (2010), Quinlan and Bates (2014), and Shildrick (2015) describe this as a human-machine assemblage and argue how this entanglement between the material and immaterial produces configurations and capacities for change. The articulations society assigns to disability shift when others can also speak to Rohan's movement as swift, agile, and powerful. Here, interferences of power and non-disabled/disabled converge to produce a sort of friction between what Sunrise needs and what Rohan wants. In unmaking disability or in making it differently through the production of access in relation to a machine, Rohan reconfigures the relationship between Sunrise and himself. As a human/machine, he is no longer just disabled, but is rather, something entirely new – more disruptive and with new capacities and possibilities. He might now be able to check his mail; to speak to a lawyer or a reporter outside of Sunrise; to build momentum in the community. Rohan, of course, did all these things from within Sunrise and without his equipment. However, with access to his devices, Rohan's capacity to resist could have been that much more.

Kim and Melissa only spoke in fleeting remarks about Rohan's life outside of the legal case, but if Rohan decided to convey the theft of his equipment to them it must have been an important element in his life. Its disappearance, would equally, have had a significant affecting quality. Rohan would have lost not just access to movement, but access to parts of this life. Rohan again made bodymind differences pertinent. He activated disability not as a *thing*, but as in relation to the other human and non-human elements. Fritsch (2013) argues that when disability is a thing, it "can be known, contained, marketed, consumed, profited from, and solutions can be found" (p. 142). However, disability in relation is "fluid, contextual, social relation" (p. 142). It is much more difficult to ignore or suppress when it is made relevant and expressed as a force intra-acting with other elements.

The examination of these moments of interference demonstrates Rohan's agential capacity to make and unmake differences and to resist dominant cultural understandings of fat/black/disability embodiment. The refusal to comply with his food preferences and the theft of his cologne and equipment only further attests to the hostile and violent experiences Rohan had to endure during his legal challenge. Melissa repeated Rohan's argument stated earlier – that the underlying reason for Sunrise's determination to evict him was because he lived longer than they ever expected. Rohan's expression of life – in all the things discussed above – was a constant reminder of his aliveness. This is contrary to the conception of fat bodies, black bodies, and disabled bodies as dying and already dead. In making his body not only alive, but one that enjoyed food, was sexual, and had a desire to explore, Rohan remade the meanings of fat/black/disabled bodies that undermined Sunrise's and Revera's business model. The next section will demonstrate how Rohan's desire for life permitted him to resist the state and achieve his goal of staying at Sunrise.

Fat

The Sheriff's refusal to remove Rohan from Sunrise was a serious matter. The Court stated as such when they said,

> A Sheriff is an officer of the court, sworn to uphold the law. Refusal by a law enforcement officer to enforce an order of the court can only serve to undermine respect for the judicial

> system and bring the administration of justice into disrepute. A Sheriff, therefore, has no discretion to refuse to execute a writ of possession (*Sunrise North Senior Living Ltd. v. The Sheriff (Regional Municipality of York)*, 2020).

After reading about the Sheriff's refusal in the court proceedings, summaries from legal analysts, and in Kim Zazour's reporting, the authors were left confounded by the Sheriff's inaction. Was this, in fact, an act of solidarity or resistance? Did the police refuse to engage on moral or ethical grounds, or because of feelings of pity or charity? Kim, thankfully, explained their reasoning. She stated, "There was discomfort around moving, Rohan." Melissa concurred with Kim's assessment of the Sheriff's inaction and clarified that it was, without a doubt, not an act of resistance. Making sense of the Sheriff's refusal to move Rohan based on discomfort was now even more challenging. What about Rohan, or the situation was so affecting? Why does *this* black man, who was found guilty in a court of law, warrant different treatment from the police and the state compared to the thousands of innocent black men murdered on the streets? The analysis suggests that it was Rohan's fat, black, disabled body that unsettled the police and allowed him to stay in place

To understand how this unfolded, one must first unpack the meaning-making around fat, black, disabled bodies in contemporary society. Intra-acting within the event-space comprised of Rohan, Sunrise, the police (and so many other elements) was also the common notions of the fat body as dying, the black body as death, and the disabled body as dead (Shackelford, 2021). Rohan was thrice-dead – his body far out of bounds – occupying spaces beyond "being, life, death, other, imagination, extravagance. . ." (Shackelford, 2021, p. 254). However, in this beyond-space, he made fatness, blackness, and cripness relevant, significant, and qualities of life and living. Shackelford (2021) speaks of this as a black fat politic of abundance intrinsically rebellious against the anti-blackness of the world. The authors would add that disability is equally abundant and tied up in the making and unmaking of blackness. Thus, Rohan lived in the abundance of his fat/black/crip-ness. He enacted this being and becoming and conveyed his desire for those expressions in the Jamaican food he selected to nourish and feed him; in the colognes he collected and applied and, in the machines, and equipment he so badly wanted back so he could move and explore. He lived his life and expressed this desire to live. This abundance for life – in fat/black/crip-ness – the authors assert, was the Sheriff's source of discomfort.

Discomfort is a culturally acceptable way of expressing disgust and revulsion against fat people. These are also all too common adjectives used to express hostility toward disabled and racialized people. However, LeBesco upends these ideas by arguing that in reading fat bodies as revolting, there is an opportunity to make this misreading political. Fat bodies, LeBesco (2001) contends, are revolting *and* thus capable of "...overthrowing authority, rebelling, protesting, and rejecting..." (p. 75). LeBesco's argument is, if fat is to be conceptualized as revolting, then it can also be considered an act of revolt. Fat is not just being acted upon or discursively imagined and reimagined through dominant or counter-dominant cultural notions but is also acting upon the human and nonhuman elements in any given space. It has, as Colls

(2007) argues, "...its own capacities to act and be active" (p. 358). Fat acted as a force preventing the police, the Sheriff, the Courts, and a multinational corporation from doing their bidding. It is in this full resistance, embodied and embedded with black-abundance, fat-revolt, and crip-desire that Rohan was able to stay 2 years past his eviction at Sunrise – what he wanted from the beginning. Rohan's bodymind already imagined as dying/death/dead caught up to his time-space, all too soon. Although he was never physically evicted from Sunrise, he also did not escape. He did, however revolt, and from that, there are lessons for fat, black, and disability scholars and activists to remember, learn from, and share.

Reimagining Long-Term Care

Rohan's choices were very limited. His family could not provide him a place to stay, even temporarily. Other retirement homes could accommodate him, but not all his belongings. His choices, therefore, were between a long-term care facility or a hospital. What he really wanted was to stay put, but Sunrise was no longer an option. Together, the healthcare and justice systems in Ontario failed to support Rohan in this effort. As disability studies scholars, and Ontario residents, it is devastating to know that the legal system would fine the province for failing to evict a man rather than charge the state for failing to house him. It's equally devastating that Rohan's options were so limited. Rohan wanted people to recognize his capacity for life (Zarzour, 2021). In this regard, Rohan's attempts to distance and separate himself from long-term care homes were an act of resistance, a recognition that he had a lot more to contribute. He imagined his life outside of long-term care. He saw too many friends die at Sunrise or be transferred away to hospitals and long-term care facilities, only to die shortly thereafter (Zarzour, 2021). He perceived that admission into long-term care would have been a death sentence (Miller, 2021, "personal communications"). Melissa expressed concern over Rohan's possible placement in long-term care. She shared Rohan's fears and expressed similar concerns about his life in long-term care. Rohan was in a state of unrest and upset, waiting to hear where he might go, surrounded by half-packed boxes prepared for the move, worried it would cause him to lose caregivers who had been with him for over a decade and whom he considered family. He had trouble sleeping during this time, experienced recurring nightmares, and left depressed and helpless (Zarzour, 2019).

According to a Canadian scoping review (Alberga, et al., 2019) on weight-bias and healthcare utilization, having an increased body mass index (BMI) impedes access to health care and studies have documented a decrease in the use of healthcare services associated with an increase in body mass index (BMI) (Olson et al., 1994; Fontaine et al., 1998; Amy et al., 2006; Aldrich and Hackley, 2010). Disability scholars have also discussed fear of using healthcare services due to weight bias and racism in healthcare (Gardiner, 2020). The authors contend that this weight-bias extended to the type of care and support that Rohan needed, it limited his personal support worker and healthcare options including his ability to select Direct Funding as a care model.

The Direct Funding (DF) Program is an Ontario-wide program that provides funding to directly eligible disabled people (referred to in the program as "self-managers) to hire and manage attendant services from their homes. Criteria for the program are set by the Ontario Ministry of Health and Long-Term Care and the funding is administered by the Centre for Independent Living in Toronto (CILT), Inc. Only after diligent assessments to meet the criteria can individuals access the funding. The program allows for recipients to have more choice and control over their own attendant care needs. The program was created following considerable disability activism, and it eventually would follow the principles of the Independent Living Movement – choice, control, freedom, equality – which emerged from the disability rights movement started in the UK and Berkeley, California (Evans, 2003; Hasler, 2003; Martinez, 2003). When the idea of self-directed care emerged, many in the disability community were speaking out against institutionalized "care" and the abuses within those systems.

DF has some very real limitations. It is important to note that it is the most cost-effective option for the support and care of disabled people, and it relies on the free labor of disabled self-managers as well as close to no benefits or opportunities for attendant, with no path to advance in their career. Kelly (2014) points to DF as a program that is monetized based on ability and care needs as defined by the Ministry rather than the self-determination of disabled people. As Hande et al. (2020) write, "DF should be one component of a broad spectrum of social care policies" (p. 27).

Due to the poor conditions in retirement congregate living, nursing homes, and long-term care homes there have been calls to increase homecare services in Ontario. Not long into the pandemic stories of abandonment, neglect, and mass loss of life spread rapidly and the significant gaps in long-term care planning and management were finally center stage (Howlett, 2021; Morocco et al., 2021). As a response, disabled activists (Jama, 2020; Schulson, 2020) are calling for the abolition of long-term care in recognition of the need for more *care at home* and not more *housed* disabled people (Home Care Ontario, 2021). Care at home would promote self-agency, ensure care, and allow a person to select their chosen community. The Canadian Red Cross (2021) states, "If given the choice, most Canadians would *choose* to age or recover at home." The Red Cross does not define homecare but provides a list of three common characteristics: (1) personal care, (2) home management, and (3) respite and companion care (Canadian Red Cross, 2021). Many models of homecare do not recognize younger, permanently disabled people as likely users of the model. This erasure is evident in the popular definitions for the model that focus on the care of seniors, individuals with temporary disabilities, and those at the end-of-life.[5] This is an interesting erasure and a gap in the system, one

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[5] Please consider this definition from Bayshore (2018): "Home care services are extensive and varied, depending on the need. Services can include meal preparation, medication reminders, companionship or assisting with errands. Home care services can also include respite care, wound care, serious injury care, or palliative care. Home care is about meeting the most basic, but essential, needs such as a friendly face dropping by for a chat or something as intimate and poignant as end-of-life care" (n.p).

that Rohan described to various news media outlets. Rohan should have had the opportunity to live in his own home and receive care throughout his life. However, the required adaptations for fat bodies are far from the minds-eye of designers of care systems in Canada. These assumptions surely created enormous barriers for Rohan. And yet, while homecare might still have been within the realm of possibility for Rohan, none of it materialized. Currently, long-term care and meager homecare provisions represent a system that operates below the threshold that would allow for the survival of disabled people. By moving to a system that addresses quality of life and care, rather than state-recognized and monetized basic body needs, disabled people, including Rohan, could live fuller, dignified lives.

The time spent reading about Rohan's life allowed the authors to reflect on less popular, more radical care models. Specifically, care collectives (see Piepzna-Samarasinha*,* 2018). Care collectives are a model of care where friends, rather than attendants or personal support workers (PSWs), provide the necessary daily assistance with living. Loree Erickson, a disability studies scholar and activist, has operated her care collective in both the USA and Canada for the past 17 years. It has become a political space for training in activism and teaching disability politics. Piepzna-Samarashinha (2018), calls Loree's care collective, "a deep possibility model, not a one-size-fits-all solution for everyone who needs care" (p. 60). What if similar model of care, adapted for Rohan, might have worked if the right support or infrastructure was present? From what others have told the authors about Rohan, he was a master at building community. When Rohan could not continue to live at Sunrise Senior Living, he quickly made significant attempts to identify community allies through pro bono legal groups, reporters, former colleagues, and influential community members and leaders. Rohan's care collective then was not only a collection of PSW's, nurses, doctors, and friends but folks concerned about disability justice in the broader community. What would it be like to imagine Rohan organizing his care at *his* home? This care would be organized to include his food preferences, his hobbies, and his equipment – and so much more. It would have meant that Rohan could have actualized more of his life and his desires. It certainly would have stifled the suffering that he experienced repeatedly at the hands of deepening and entangled systemic oppressions. It is in the realm of possibility that Rohan would have been able to create a little utopia.

Conclusion

Fady learned of Rohan's situation in 2018 from Kim's reporting. At the time, he was on the board of the Centre for Independent Living in Toronto (CILT) Inc and thought he could help in that capacity. He emailed the Executive Director, at the time, Sandra Carpenter. Fady figured that Sandra, a life-long disability activist, would know what to do. Sandra's response was quick but defeating. She said, "I'll definitely look into it. The trouble is he is bariatric and so not many attendant service providers can accommodate that." She explained, "For example they would need extra wide wheel-chairs [and] doorways, maybe two person transfers. A definite hole in the system." Comments about "holes in the system" are abundant but after following Rohan's care, the flaws in the systems and institutions he encountered seem more akin to cavernous pits than just a few holes. Many mourn for those who have fallen in, who are pushed in every day – those whose stories are heard, analyzed, and remembered, and the many, many more that disappear without any discussion.

The authors mourn with Rohan's family and friends for their loss and with Kim and Melissa who tried for nearly 2 years to bring attention and justice to Rohan's situation. The analysis has hopefully brought further scrutiny to Rohan's case and to the fatphobia, anti-black racism, and ableism he experienced and that make up many disabled people's experiences in the nursing home-industrial complex. However, this chapter is also a celebration of Rohan's life and his commitment to living. Rohan's resistance against the state was purposeful, meaningful, but also time limited. There is a temporality to this resistance. The state and its actions killed him. But Rohan made his mark – claiming his subjectivity at the intersections. He actualized intersectionality-as-interference – occupying conceptual and material space before state violence could erase him. Despite the state conceiving of him as disposable, his agential interference – enacting a crip-desire, within a black body that embraced excess as a mode of refusal was a spirit that the state could not destroy. Other marginalized people, both inside and outside long-term care, enact similar resistances to Rohan's. As disability studies scholars, analysis of power relations and agency considers patterns of interference in emergencies with material things to ensure they are not territorializing expressions of resistance. In truth, witnessing and acknowledging these acts of resistance and expressions of life render unintelligible any justification for the violence, harm, and hate too many disabled people experience in care institutions.

This chapter has argued that Rohan expressed a desire for life, through his relation to material things that made and unmade fatness, blackness, and disability in such a way that it brought attention and scrutiny on to his body, which was already deemed dead and dying. In focusing on the relational ontology of fatness, blackness, and disability, the authors have shown the fluidity of these categories, and their interconnections, to demonstrate how Rohan enacted a desire for difference through fat/black/crip-ness that upended the social script – and allowed him to thwart police and the courts. *Fat/black/crip becoming* had an affective political intensification on those in positions of power, which allowed Rohan to get what he wanted – to stay put, for as long as possible.

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Part VII

Monitoring and Indicators of Disability Rights

Monitoring and Indicators of Disability Rights: Introduction

36

Radoš Keravica

Abstract

This introduction offers a brief overview of the key challenges that the stakeholders involved in the monitoring of the implementation of the UN Convention on the Rights of Persons with Disabilities are facing, opportunities for engagement with national and international human rights mechanisms and the best practices of participatory monitoring led by disabled people and their representative organizations. It introduces readers to the content of seven chapters written by contributors which come from different spheres of work and include activists from civil society, human rights professionals from intergovernmental organizations, academic researchers, and disabled people themselves. The readers will be able to get a glimpse of the contributions which tackle some of the contemporary issues in the field of monitoring and indicators of disability rights mapping out the challenges and potential solutions to advance human rights monitoring holding governments accountable to the population of disabled people worldwide.

Keywords

Disability rights · Monitoring · UN Convention on the Rights of Persons with Disabilities · Indicators · Sustainable Development Goals

The UN Convention on the Rights of Persons with Disabilities (CRPD) brought into force in 2006 has marked an important milestone in the global struggle of disabled people for equal enjoyment of human rights. The drafting process of the CRPD had seen unprecedented participation of disabled people and their organizations, unparalleled in any other human rights treaty before it. The CRPD has been ratified so far by 184 States Parties and after the UN Convention on the Rights of the Child, it is the

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most ratified treaty in the corpus of international human rights law (UN DESA, 2022).

The Convention is a hybrid human rights treaty in so far as it includes both civil and political and economic, social, and cultural rights. It also comes close to creating new rights or at least innovates the existing human rights standards as it introduces some of the concepts which had never before been mentioned in international human rights law, such as independent living or supported decision-making (Megret, 2007). That being said, not only does it require profound and carefully planned legal reforms, it requires changes in how society views and treats disabled people and changes in attitudes and professional practices which result in segregation and isolation of disabled people.

After the ratification, most of the States Parties have engaged to some extent in legal reforms in order to align domestic legislation with the CRPD provisions. The CRPD Committee has consistently been pointing out in the first cycle of state reporting the need to bring the domestic legislation in compliance with the CRPD norms. Now, more than 15 years after the CRPD has been brought into force, it seems that the onus is shifting toward the need to ensure full implementation of reformed legal frameworks at the national levels and the CRPD as a whole. Since the CRPD is to a significant extent innovative human rights treaty demanding profound changes in society, it might seem easier to identify the practices which are not compliant with the standards enshrined in the CRPD, rather than knowing what exactly should be done to make the full enjoyment of human rights a reality for disabled people. OHCHR defines monitoring as “a broad term describing the active collection, verification and immediate use of information to address human rights problems” (Office of the High Commissioner for Human Rights, 2001). This definition begs the question of who is supposed to collect the information and how, which information is needed, or how that information can be used to address human rights problems. With those questions about monitoring in mind, we can say with certainty that it becomes increasingly important to establish independent national monitoring mechanisms with strong involvement of disabled people and DPOs which would have resources and skills to monitor the implementation of the Convention on an ongoing basis. Participation of disabled people in the monitoring process should ensure that their lived experiences are used to provide evidence of human rights violations but should also inform the advocacy agendas of civil society actors and ultimately the implementation of the CRPD.

The CRPD monitoring and reporting is not the only international mechanism on disposal for disabled people to track societal progress. The Sustainable Development Goals (SDGs) or Agenda 2030 is an internationally agreed set of goals adopted by the UN General Assembly (UNGA) which succeeded the former development agenda known as the Millenium Development Goals (MDGs). The SDGs do not have a legally binding nature as the human rights treaties but rather represent the world’s vision of the future and aspirations to reach a more equitable and sustainable society. Although based on voluntary compliance, the SDGs provide for substantial institutional mechanisms to monitor the progress made by the states and for the engagement of disabled people and their organizations in the process of monitoring.

However, disabled people should be aware that the SDG's potential to bring about desired changes is not uncontested. The SDGs are criticized for failing to challenge the existing institutional order of the world's economy which generates inequalities and poverty in the first place (Pogge & Sengupta, 2015). The lack of structural changes in how the global economy operates ensures the continuity with the prioritization of commercial interests of transnational cooperation weakening the power of states to provide for their citizens and guarantee their human rights (Josephsen, 2017; Eisenmenger et al., 2020). Despite the claims of universality and ideological neutrality, the SDGs seem to perpetuate the neoliberal politics of development and in this regard are far from being ideologically neutral. Neoliberal politics promotes economic growth rather than redistribution policies as the main vehicle for the reduction of inequalities (Weber, 2017). Its ideological premises underpin the liberalization of markets, commercialization, and commodification of goods and services including public ones such as health care or social services which have vital importance for disabled people. Disabled people have experienced detrimental effects of the neoliberal commitment to reduce the state's role in funding and provision of health and social care as part of the austerity measures (Sakellariou & Rotarou, 2017). A stark example of this is the reform of disability benefits in the UK which tightened eligibility criteria and led to significant cuts to financial support for disabled people undermining their right to independent living (Cross, 2013). These reforms even triggered an inquiry procedure under the UNCRPD and an investigation of the UNCRPD Committee which established that grave or systematic violations of the rights of disabled people have been committed by the UK Government (CRPD Committee, 2016).

These developments tell that the disability movement needs to be aware of the weaknesses of the current international human rights and development mechanisms and to remain vigilant and understand the impact of underlying social structures that cause disablement. Monitoring should help to develop such understanding and inform disability activism because disability justice will only be achieved when disabling social structures that lead to our marginalization are identified and dismantled.

This section seeks to explore the latest developments in the field of disability rights monitoring. The chapters prepared by the contributors to this section cover different aspects of disability rights monitoring which will contribute to answering the questions posed in the previous paragraph. Here, we offer a brief overview of the content of the chapters included in this section.

Colin Caughey and Hanxu Liu in ► Chap. 37, "Role of National Human Rights Institutions and Organizations of Persons with Disabilities in the National Monitoring of the CRPD," explore the normative framework of the CRPD as it concerns monitoring at the national level. The CRPD Article 33 has envisaged a robust system of monitoring of the CRPD implementation. Its text includes a standalone article on monitoring (Article 33) drawing from the decades-long experiences and lessons learnt from monitoring of other human rights law instruments. Among the key requirements of Article 33 is the involvement of persons with disabilities and their representative organizations in the process of monitoring, both through national and international monitoring mechanisms. Colin and Han in their research examine the requirement for the State Parties to set up independent monitoring frameworks. They draw from their research of organizational models of independent monitoring frameworks and analyze the examples of designation of the National Human Rights Institutions (NHRI) as the independent monitoring frameworks while paying special attention to the issue of involvement of DPOs in the work of such frameworks and monitoring processes.

Victoria Lee and Juan Ignacio Perez Bello in ▶ Chap. 38, "Bridging the Gap: Harnessing the Synergies Between the CRPD and the SDG Monitoring Frameworks," analyze the ways of strengthening complementarity and synergies between the monitoring frameworks of the CRPD and SDGs in order to harness their potential to ensure full inclusion of disabled people in contemporary societies. Both instruments and their monitoring frameworks create important opportunities to advance the rights of persons with disabilities through data collection and disaggregation, the use of indicators to track progress, as well as the participation of persons with disabilities and their representative organizations. Victoria and Juan Ignacio examine the possibilities for DPOs to engage in the monitoring processes under both instruments and they also present the SDG-CRPD resource package developed by the Office of the UN High Commissioner for Human Rights (OHCHR), particularly its human rights indicators and data sources guidance with an aim to contribute to converging and consolidating efforts toward a disability-inclusive 2030 and beyond.

Elizabeth Lockwood in ▶ Chap. 39, "Disability Rights Monitoring: Focus on the Sustainable Development Goals," explores the evolution of advocacy of the inclusion of persons with disabilities into the 2030 Agenda, participation in follow-up and review mechanisms, and how this, in turn, influences national policies. She argues that despite incredible efforts, persons with disabilities remain left behind after five years into the implementation of the SDGs, particularly due to the lack of disability data to monitor the SDGs. Further on, she underlines the importance of the engagement of DPOs in advocacy efforts to make sure that the States collect and disaggregate data on disability to enable evidence-based policymaking in line with the CRPD standards and toward the fulfillment of the ambitious Agenda 2030.

Steven Allen and Sandor from Validity Foundation reflect on the challenges that disabled people faced globally during the pandemic of COVID-19. In ▶ Chap. 40, "COVID-19 Disability Rights Monitor: State Measures' Impact on Persons with Disabilities during the Coronavirus Pandemic," they draw from the major global initiative the COVID-19 Disability Rights Monitor which was set up to monitor the impact of COVID-19 impact on disabled people worldwide. They reflect on the methodology used to monitor the impact of the pandemic on disabled people and highlight the significance of participatory monitoring which relies on people's testimonies and the significance of working in a transnational coalition of disability organizations to collect monitoring data and reveal human rights violations. They show the findings of the survey and share representative testimonies from persons with disabilities and other respondents.

Teodor Mladenov as a member of the Independent Living Research Network offers an account of the engagement of the international DPO – European Network on Independent Living (ENIL) in the process of monitoring the implementation of CRPD Article 19 at the European level. In ▶ Chap. 41, "Independence and Its Meaning: ENIL's Monitoring of Article 19 as a Struggle for Hermeneutical Justice," Teodor explores the efforts of disabled people's independent living movement to negotiate the meaning of independence and conceptualizes ENIL's monitoring of the implementation of Article 19 of the CRPD as a struggle for hermeneutical justice. ENIL's understanding of independence as having a choice and control in one's everyday life, including choice and control over one's support, has guided ENIL's monitoring of deinstitutionalization reform and personal assistance schemes in Europe that are discussed in the chapter as instances of disabled people's organized collective struggle for hermeneutical justice. This highlights the importance of monitoring as an emancipatory tool through which the disability movement can promote its philosophy and disability rights as a whole.

Sonja Vasić and Emma Matreniuc in ▶ Chap. 42, "Disability Rights Monitoring in Practice: Applying Holistic Participatory Methodology," offer an account of the personal impact experienced during the participation in the Disability Rights Promotion International (DRPI) Project (Rioux, 2017) in Europe by two women disability rights activists with the living experience of disability. Sonja and Emma were involved in DRPI Project in Eastern Europe in different roles within the project, supporting the collaborative participatory country monitoring projects in the region. They explain the key features of DRPI's holistic participatory methodology of disability rights monitoring and share their experiences of participation in the project. They examine the personal impact they experienced in the monitoring process and critically reflect on the impact of participation in the monitoring process for the disability movement as a whole. Their chapter reminds us of the emancipatory potential of participatory monitoring for disabled people and their movement. It underscores the strong message that the process of monitoring is equally important as its results. In the participatory monitoring process, DPOs can come together to work in cross-disability coalitions, learn about their rights, share their testimonies of human rights violations, and use evidence to shape their common advocacy agendas.

Sophie Pecourt and Silvia Quan share their experience of working with the Making it Work (MiW) methodology. In ▶ Chap. 43, "Protecting Women and Girls with Disabilities from Violence and Upholding Their Rights: Making It Work Methodology," they reflect on the utility of MiW methodology to collect information on best practices of CRPD implementation shifting the focus from collection of data on human rights violations to collection of data on what works best in the process of CRPD implementation. They explore MiW methodology as applied to the initiative to prevent, eliminate, and respond to violence, abuse, and exploitation against women and girls with disabilities and demonstrate that placing persons with disabilities, particularly women with disabilities, as key and central actors in the implementation and monitoring of the CRPD, is a successful road for their empowerment.

It is our hope that this collection of chapters on disability rights monitoring will shed light on key challenges and lessons learnt from the engagement of DPOs in the processes of monitoring pertaining to the CRPD, but also to SDGs at the national and international levels. These insights from fellow advocates for disability rights cover a range of topics including but not limited to the normative framework of the CRPD as it concerns the monitoring, its methodologies, and participation of disabled people and their organizations in data collection and reporting. Further, the contributors to this section focus on the synergies and differences between the CRPD and the SDGs and their systems of monitoring, the use of human rights indicators for monitoring purposes, the use of monitoring to uncover specific forms of human rights violations, or the emancipatory potential of monitoring for disabled individuals and disability movement as a whole.

The contributors to this section of the handbook come from different backgrounds and we are proud that among them there are prominent disability activists working in national and international civil society organizations, United Nations, academia or development agencies, and disabled people themselves. We are convinced that their insights will represent a significant resource for all those wishing to engage in disability rights monitoring or merely to learn more about it and at the same time will provide us all with an impetus for joint reflection.

It seems that it is now important, perhaps more than ever, to use the CRPD and its system of disability rights monitoring to systematically collect data and report on the human rights violations disabled people are facing during the pandemic of COVID-19 but also in the period of societal recovery. The times of crisis as we have seen after 2008 and the financial crisis that ensued followed by austerity programs worldwide represent a threat to previously attained levels of enjoyment of human rights and disabled people are among the first groups to experience the setbacks (Macdonald & Morgan, 2021). The present conflict in Ukraine coupled with pandemic effects is already causing economic instability. The effects of the high inflation rates, increased cost of living, energy crisis, and refugee crisis will certainly influence national economic and social policies worldwide. As some countries are announcing significant increases in their military spending, it can be assumed that the spending on disability may come under attack.

Thus, it is important that disability movement monitors the impact of emerging crisis and policies which form the response to this crisis. The social model of disability as the “big idea” of the disability movement should be at the heart of monitoring efforts as the social model points toward the sources of disablement which have nothing to do with people’s impairments but lie in the social structures that generate the barriers and social exclusion that disabled people face (Oliver & Barnes, 2012; Beckett & Campbell, 2015).

The most important way to do this data collection and monitoring in the future will be by developing sustainable, independent, and robust systems of human rights monitoring at the national level. Such systems should be properly funded and should apply periodically, on a regular basis, a consistent methodology to compile the sets of quantitative and qualitative data including the testimonies of disabled people. Equally important, disabled people and their organizations should be directly involved in the monitoring processes. Monitoring should not be the exercise reserved only for "experts" (disabled or nondisabled) with specialized knowledge of the CRPD who get hired to draft reports on the realities of disabled people without consulting them. Instead, the monitoring process is equally important as the result and disabled people across all impairment, age, and gender groups should be engaged in it. The monitoring process should be participatory and emancipatory, in so far as it should create the space for disabled people to voice their views and tell about human rights violations they experience. It should also help them to learn about their human rights, sources of disablement and commonalities with disabled people with other impairments than theirs, and provide them with the possibilities to engage in disability activism. The methodology of holistic and participatory disability rights monitoring developed under the global and collaborative Disability Rights Promotion International (DRPI) project has come furthest toward achieving this purpose (Disability Rights Promotion International, 2011). Tested in more than 40 countries worldwide and based on an emancipatory paradigm it sought to build the capacities of disabled people at the grassroots level to monitor their rights equipping them with the knowledge and tools to conduct participatory disability rights monitoring drawing on their expertise by experience.

It is our hope that this section will offer important lessons learned through the recent monitoring processes in which disabled people were engaged. Our contributors attempted to answer the questions of what do we monitor, what kind of data we need to collect, and how and where do we report the findings if we are to see long-awaited changes. Let their contributions be the starting point for further development of monitoring practice and joint deliberations on the issues raised in this section.

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Role of National Human Rights Institutions and Organizations of Persons with Disabilities in the National Monitoring of the CRPD

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Contents

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Abstract

This chapter explores the relationship between national human rights institutions (NHRIs) and organizations of persons with disabilities (OPDs) in the context of the UN Convention on the Rights of Persons with Disabilities (UNCRPD). The chapter focuses on Article 33(2) of the UNCRPD; it analyses the obligation placed on states to establish an independent monitoring framework and how states are meeting this obligation in practice. It looks at the different models which states have adopted when developing their monitoring frameworks, noting that the designation of an NHRI within the framework as the independent monitoring mechanism has in practice been shown as the strongest guarantee of both independence and effectiveness. The chapter considers the opportunities which the designation of an NHRI within the independent monitoring framework presents to OPDs. The unique characteristics of NHRIs are considered. Noting these, a number of potential opportunities for collaboration between NHRIs and OPDs are considered with reference to relevant examples. Overall the chapter highlights the need for a more detailed appreciation of the relationship between NHRIs and OPDs along with the need to consider what achievements can be made through effective collaboration.

Keywords

National human rights institutions · Influencing · International examination · Monitoring · Organizations of persons with disabilities · Investigations · Collaboration · UNCRPD article 33

Introduction

When the UN Convention on the Rights of Persons with Disabilities (hereinafter CRPD or Convention) was opened for signature, it was anticipated that it would lead to procedural innovation at the domestic level. Including it was hoped that the establishment of institutional architecture for the implementation of the CRPD would act as an engine for law reform (Quinn, 2009a, b, pp. 47–48; UNCRPD, 2007). This architecture is constructed around three pillars consisting of a government focal point, a reinvigorated civil society, and an independent monitoring framework.

Some 15 years since the Convention was opened for signature, it seems to be an appropriate time to take stock of how this architecture has been developed in practice and whether the promise of innovation has been delivered. This chapter will focus on the latter two pillars considering how states have complied with the obligation to establish an independent monitoring framework and the opportunities which this presents to civil society. The chapter highlights that central to the success of both pillars is the relationship between national human rights institutions (hereinafter NHRIs), designated within a monitoring framework and civil society organizations, particularly organizations of persons with disabilities (hereinafter OPDs).

During the negotiation of the CRPD, civil society organizations and NHRIs collaborated effectively to influence the development of both the substantive and procedural articles within the Convention. Echoing the international disability movement's mantra of "nothing about us without us," the CRPD places general and specific obligations on the state to involve civil society in the implementation of the Convention (UNCRPD, 2007, Article 4.3, 33.3 and 32.1).

NHRIs are "State-mandated bodies, independent of government, with a broad constitutional or legal mandate to protect and promote human rights at the national level" (Paris Principles, 1994). NHRIs are accredited by the Global Alliance of NHRIs (hereinafter, GANHRI) on the basis of their compliance with the Paris Principles relating to the status and functioning of national institutions for protection and promotion of human rights (hereinafter the Paris Principles). The Paris Principles are referred to within Article 33(2) which puts in place a requirement on State Parties to establish a framework, including an independent mechanism to monitor the implementation of the Convention (Degener, 2016, p. 31; Quinn, 2009b, pp. 47–48). As we will set out below in practice, NHRIs are the presumptive nominee as the independent mechanism. In practice many independent monitoring frameworks are single entity frameworks. NHRIs designated as the independent monitoring mechanism therefore also effectively make up the entirety of the monitoring framework.

This chapter aims to consider the legal aspects of the independent monitoring mechanisms as required by the CRPD and investigate states' obligations, civil society's role under such mechanisms, and some current issues in practice. With a focus on the independent monitoring mechanism, this chapter considers how civil society organizations, especially OPDs, can collaborate with NHRIs designated as the independent mechanism to bring about change. We introduce an overall discussion, rather than a comprehensive reflection on the current practice of CRPD monitoring, drawing on existing studies and documents from online database[1] of the Committee on the Rights of Persons with Disabilities (hereinafter CRPD Committee or Committee).

The following discussion is developed in four sections. First, section "International Normative Framework: National Monitoring and Civil Society's Participation" provides an insight into the normative frameworks under the CRPD regarding independent monitoring mechanisms and the participation of civil society, especially OPDs. Section "Current Situation of National CRPD Monitoring" looks into the implementation of such mechanisms among states and then discusses the effective collaboration between the NHRIs and civil society organizations in section "Effective Collaboration Between Independent Monitoring Frameworks and Civil Society Organizations." The last section provides some concluding remarks.

International Normative Framework: National Monitoring and Civil Society's Participation

The OHCHR (2009) published a thematic study on the structure and role of national mechanisms for the implementation and monitoring of the CRPD, followed by a guidance document in 2014 (Conference of States Parties to the Convention on the

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[1] See https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/TBSearch.aspx?Lang=en

Rights of Persons with Disabilities). Guidance issued by the CRPD Committee by way of its concluding observations and general comments have further prescribed the form and function of independent monitoring frameworks (CRPD Committee, 2018d). The CRPD Committee have also issued specific guidelines on the independent monitoring frameworks and their participation in the work of the Committee (CRPD Committee, 2016a, b). Despite these additional sources of guidance, a number of ambiguities remain relating to independent mechanisms, which we will seek to address in this section.

The CRPD was negotiated at a time at which the effectiveness of the treaty body system was under scrutiny and consideration was being given to adapting practices and procedures regulating treaty body examinations to make them more effective (Pillay, 2012, as cited in Guernsey 2018). During the negotiation of the CRPD, a number of proposals for innovating the international examination process were put forward. However, as the negotiations progressed, it became clear that states were unwilling to subscribe to new methods of international monitoring (Stein & Lord, 2010, p. 689, as cited in Combrinck, 2018, p. 1066). The negotiations focused on developing innovative arrangements at the domestic rather than at the international level (Raley, 2016, p. 138). As a result the CRPD represents "a clear improvement for human rights implementation" at the domestic level (Marianne Schulze, 2013, p. 209). The CRPD puts in place a dual approach to oversight, with responsibility for international oversight resting with the Committee and responsibility for domestic oversight with the independent monitoring framework (Ferrajolo, 2017, p. 610). We would add to this assessment that the CRPD improves human rights at the domestic level through requiring states to ensure the participation of persons with disabilities in the implementation process and to support their participation in the monitoring framework.

The CRPD Article 4(3) places a specific obligation on governments to "closely consult and actively involve" persons with disabilities including children and their representative organizations in "decision-making processes concerning issues related to persons with disabilities." This obligation is closely related to the right to political and public life protected by Article 29 of the CRPD. Article 29 (b) emphasizes the value of participating through NGOs and associations, especially OPDs that represent people with disabilities at international, national, regional, and local levels.

OPDs should be systematically and openly consulted and involved in decision-making processes related to monitoring the CRPD, in a "meaningful and timely manner," which requires states to ensure accessibility and provide reasonable accommodations in relation to information, communications, the physical environment, and national funds (CRPD Committee, 2018d, para. 22). By way of general comment, the CRPD Committee have elaborated on the requirements of Article 4(3). The CRPD Committee have made clear that OPDs should be systematically and openly consulted and involved in the development of CRPD implementation measures, in a "meaningful and timely manner," which requires states to ensure accessibility and provide reasonable accommodations in relation to information, communications, the physical environment, and national funds (CRPD Committee, 2018d, para. 22).

The CRPD at article 33(2) makes provision for the establishment of an independent monitoring framework, it provides:

> *States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.*

From initial observation, this provision requires a state to have regard to the Paris Principles when designating the independent monitoring mechanism. The OHCHR stated that NHRIs are the "natural core entities of the monitoring framework at the national level" (OHCHR, 2009, para. 78).

The text of Article 33(2) is not prescriptive as to the role, powers, and composition of the framework (Conference of States Parties to the Convention on the Rights of Persons with Disabilities, 2014, para. 8). States have broad discretion to establish an independent monitoring framework in line with their domestic arrangements (Lorion, 2019, pp. 234–258). Article 33(3) also places a specific obligation on states to ensure "civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process." The precise form this participation should take is somewhat unclear (Conference of States Parties to the Convention on the Rights of Persons with Disabilities, 2014, para. 8). Some commentators have suggested that the Article 33(3) obligation mirrors the general obligation contained in Article 4(3) (Quinn, 2009a, p. 252). However the CRPD Committee by way of its general comment have made clear that Article 33(3) is more extensive than Article 4(3) amounting to an obligation to "ensure their effective participation in the processes of the independent monitoring frameworks" (CRPD Committee, 2018d, para. 39). This is clearly greater than the Article 4(3) obligation which is focused around the government's consultation exercises (CRPD Committee, 2018d, para. 21).

Composition of the Framework

The OHCHR has made clear that Article 33(2) does not "prescribe a unique organisational form for the monitoring framework" (Conference of States Parties to the Convention on the Rights of Persons with Disabilities, 2014, para. 19). In practice many independent frameworks are single entity frameworks. In such contexts, the terms framework and mechanisms are often used interchangeably (Murray & Johnson, 2013, p. 110).[2]

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[2] Also see the General Comment No.7, where the CRPD Committee refers to the national structure under Article 33(2) as "independent monitoring frameworks."

The CRPD Committee have not set out its preferred composition of an independent monitoring framework. However, it is notable that in its concluding observation on Spain and New Zealand, the Committee commended the state for its monitoring framework. In both states, the independent framework is composed of an A status NHRI and an OPD. The Committee noted that Spain was "*in full compliance with Article 33(2)*" (CRPD Committee, 2019d, para. 6). However within the General Comment No. 7, the Committee did not suggest that states were required to designate an OPD as part of the independent framework. The general comment acknowledges that NHRIs "play a key role in the monitoring process of the Convention" (CRPD Committee, 2018b, para. 36). Indeed the CRPD Committee in their concluding observations have consistently emphasized that within a monitoring framework, a State Party "must have an institution that is in compliance with" the Paris Principles (CRPD Committee, 2014a). As set out above, the OHCHR considers that NHRIs are best placed to perform this role. Academic scholars similarly have put forward the view that the inclusion of an NHRI is best practice (The Center for Disability Law and Policy, 2016, p. 13). The Committee in general appear content for the framework to be composed solely of an NHRI, for instance, in its concluding observations on the Czech Republic the Committee recommended that "the office of Ombudsman should be entrusted with the mandate as the independent national monitoring mechanism" (CRPD Committee, 2015a). Similarly the Committee recommended that the Canadian Government "formally appoint the Canadian Human Rights Commission as the independent monitoring mechanism," a recommendation supported by OPDs in Canada (CRPD Committee, 2017b, para. 55(b)). While they are content for an NHRI to be solely designated, the Committee have consistently recommended that independent frameworks should be required to ensure the "full involvement of organizations of persons with disabilities in its monitoring tasks under the Convention" (CRPD Committee, 2017b, para. 55(b)). Therefore while a state may choose not to designate an OPD within the independent monitoring framework, it must still facilitate their involvement in other ways.

Independence of the Framework

The wording of Article 33(2) is ambiguous as to whether the requirements of independence relate to the entirety of the framework or to the independent mechanism alone. It has been suggested that all bodies within the framework "need to be compliant with the Paris principles" (Mental Disability Advocacy Center, 2011). However Quinn and Crowther (as cited in Mental Disability Advocacy Center (2011, p. 63) in a guidance document produced for the Asia Pacific Forum have, in our view, correctly set out that, "the best interpretation is that while the designated independent mechanism must comply with the Paris Principles, the other entities in the framework have to exhibit some functional independence from the executive in order to be effective." This view reflects the established approach of the CRPD Committee which has recommended the removal of state bodies from the independent framework when they are considered to lack independence (CRPD Committee, 2015c).

In their concluding observations, the CRPD Committee have consistently highlighted that compliance with the Paris Principles is the key test of an independent mechanism's independence (CRPD Committee, 2019e). In the case of Belgium, the Committee specifically recommended that the state ensure the accreditation of the Interfederal Center for Equal Opportunities as an A status NHRI (CRPD Committee, 2014a).

The CRPD Committee have emphasized the need to ensure separation between independent monitoring and implementation activities stating that "representatives of departments and units involved in the implementation of the Convention" should not be involved in the monitoring framework (Committee on the Rights of Persons with Disabilities, 2018b, para. 20).

While there is a need for a clear separation between implementation and monitoring, effective monitoring will inevitably involve extensive engagement with the state, and monitoring frameworks will draw on the state's own data collection systems (Aichele, 2018, p. 1000). Conversely an effective plan for implementing the CRPD will incorporate extensive monitoring by the state. For instance, a state must monitor uptake of programs to support persons with disabilities. The independent monitoring framework may advise the state on its monitoring arrangements, and it may input to its analysis. However, in doing so it should maintain a "cordon sanitaire" between independent monitoring and implementation (Quinn, 2008, as cited in Aichele, 2018, p. 984). Contributing to state efforts to monitor implementation should not hinder or undermine the capacity of the independent monitoring framework to engage in its own independent monitoring activities.

Designation of an Independent Mechanism

Article 33 requires states to formally designate an independent mechanism. However this designation is not a pre-requisite for ratification. Some states have ratified the CRPD without establishing an independent mechanism (Birtha, 2013; UN Human Rights Council, 2016). An analysis of concluding observations issued by the CRPD Committee suggests that around a third of all states examined were yet to have designated an independent mechanism.[3]

Upon ratifying the CRPD, the Zambian Government implied that the Zambian Human Rights Commission had been designated as its independent mechanism. However no formal designation had taken place. In her mission report on Zambia, the UN Special Rapporteur on the rights of persons with disabilities (hereinafter Special Rapporteur) made clear that the official designation of the Zambian Human

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[3] 34 of 91 concluding observations issued include a recommendation that the State designate an independent mechanism or framework in line with Article 33(2).

Rights Commission was required (UN Human Rights Council, 2016, para. 26). This example underscores need for a formal process of designation.

The Committee have made clear that the monitoring framework must have "a stable institutional basis that allows it to operate properly over time and that it is appropriately funded and resourced" (CRPD Committee, 2019d, para. 54). The Committee have not set out in detail the steps which a state should take in designating an independent mechanism.

NHRIs must be vested with competence to promote and protect human rights and should be given as "broad a mandate as possible" (UNGA, 1994, paras 1–2). The Paris Principles require that an NHRI mandate is "clearly set forth in a constitutional or legislative text." This suggests that all accredited NHRIs should have a sufficient mandate to protect and promote the CRPD. However in practice, an NHRI's mandate may be constrained by the domestic legal framework (Murray & Johnson, 2013, p. 93). In a number of cases, the Committee have recommended that an NHRI designated as the independent mechanism be provided with a clear mandate and with sufficient authority to perform its role (Committee on the Rights of Persons with Disabilities, 2018a, para. 60). While the Committee have on occasion recommended that the founding legislation of an NHRI be amended to reflect its role as an independent mechanism, this has not been a consistent recommendation (CRPD Committee, 2017a, para. 63). In practice many NHRIs have been designated as an independent mechanism without amendments being made to their legal basis (Gauthier de Beco, 2011, p. 42).

Resourcing of Independent Mechanisms

Aichele points out that, "the CRPD Committee has indefatigably claimed that the framework must include adequate resources" (Aichele, 2018). The CRPD Committee have consistently recommended that State Parties "provide adequate funding for the functioning of an independent mechanism" (CRPD Committee, 2017b, para. 58). Within their guidelines, the Committee provide that the State Party must, "*further equip them with additional and adequate budgetary and skilled human* resources to *appropriately discharge their mandate under Article 33(2) of the Convention*" (CRPD Committee, 2016b, para. 15). The Committee increasingly consider whether an NHRI designated as the independent mechanism have sufficient resources to carry out the role. For instance, the Committee recommended that the Rwandan Government "allocate human, technical and financial resources that are sufficient in both quality and quantity to the National Commission for Human Rights to enable it to effectively perform its mandate" (CRPD Committee, 2019b).

In practice research by the OHCHR, Europe Office indicates that, "The independent mechanisms generally received no additional funding to promote, protect and monitor the implementation of CRPD. No budget has been provided following their designation" (Gauthier de Beco, 2011, p. 42). The Danish Institute of Human Rights was provided with additional funding on its designation as the independent mechanism and continues to receive specific funding for monitoring the CRPD which has facilitated the development of a specific CRPD unit within the Institute (Gauthier de Beco, 2011, p. 42).

Within General Comment No.7, the CRPD Committee have specifically emphasized the need for OPDs to receive funding to facilitate their participation in the independent monitoring framework (CRPD Committee, 2018d, para. 39). This funding should presumably be administered by the state.

Role of Independent Mechanisms

Reflecting the language of the Paris Principles, Article 33(2) sets out that the role of an independent mechanism is "to promote, protect and monitor implementation of the Convention." Within the Committee's Guidelines on independent monitoring frameworks, it is set out that promotional activities include awareness raising, provision of advice on legislation, research, and reporting including to the UN system. The Guidelines emphasize that independent monitoring frameworks should be able to issue reports "at their own initiative" (CRPD Committee, 2016b). The protection activities include complaints handling, investigations, and participating in court proceedings. The monitoring role of the independent mechanism includes the "development of a system to assess the impact of the implementation of legislation and policies," including the development of indicators and databases. The Paris Principles do not specifically address the monitoring activities of an NHRI. The focus of NHRI monitoring activities has tended to be on the identification of violations. The monitoring activities envisaged for independent monitoring frameworks appears to be more broad based and more closely linked to the policy process (Quinn, 2009a, p. 227). The performance of this more expansive monitoring role is likely to require additional financial and human resources.

Relationship with Organisations of Persons with Disabilities

The CRPD Committee have made clear that the independent monitoring framework must "ensure the full involvement and participation of persons with disabilities through their representative organizations in all areas of its work" (CRPD Committee, 2016b, para. 18).

Within General Comment No. 7, the CRPD Committee have elaborated that independent frameworks should ensure the participation of persons with disabilities and their representative groups, "through formal mechanisms, ensuring that their voices are heard and recognized in its reports and the analysis undertaken." Since the publication of General Comment No. 7, the Committee have become more prescriptive in their recommendations relating to Article 33. The Committee have consistently recommended that NHRIs designated as independent mechanisms adopt formal procedures to facilitate the participation of persons with disabilities in their monitoring activities (CRPD Committee, 2019d). The Committee have also more consistently emphasized the obligation on the state to provide OPDs with the necessary funding to ensure their participation (CRPD Committee, 2018c, para. 56).

Current Situation of National CRPD Monitoring

At the time of writing, the CRPD Committee have issued concluding observations relating to 91 states. In all but one set of concluding observations, the Committee have considered the independent mechanisms. Through reviewing the CRPD Committee's concluding observations, the reports of the Special Rapporteur's country visit procedures, and previous independent studies, a number of trends can be identified in the composition of independent monitoring frameworks.

There is a notable trend of designating an NHRI either solely or jointly as the independent monitoring framework. The designation of an NHRI as the independent mechanism is clearly seen by the Committee as way of guaranteeing its effectiveness. Before considering the essential features of an independent monitoring framework, we will briefly consider the features of an NHRI which makes them suitable to this role.

The key feature of an NHRI is its independence from the state. A body is only recognized as an NHRI when it has been accredited by an independent UN system which assess the body against the Paris Principles and provide it with a grading depending on its level of compliance (GANHRI, 2017). Once initially examined, an NHRI is subject to a quinquennial review and may have its status downgraded. While the accreditation system has been subject to criticism, it provides an open internationally recognized procedural check on the independence of an NHRI which reviews its legal framework, its budget, and its activities.

GANHRI, in particular through its Sub-Committee on Accreditation (hereinafter, SCA), provides NHRI support and assistance in safeguarding its independence. The OHCHR emphasizes that independence is guaranteed through legal safeguards and also through organizational culture (OHCHR, 2009). NHRIs foster a culture of independent thinking and analysis which safeguards them against being co-opted from the state.

As a state institution with a defined legal mandate, an NHRI brings permanence to human rights monitoring. Disability Rights Promotion International highlights that durable human rights monitoring "is not a snapshot but an on-going video."[4] NHRIs have the capacity to establish monitoring tools which track human rights developments in the long term. For instance, a number of NHRIs have established innovative human rights tracker tools which track implementation of the treaty body recommendations.[5]

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[4] Disability Rights Promotion International available at http://drpidisability.apps01.yorku.ca/resources/DRPIProgRep/Chapter1

[5] See, for instance, the New Zealand Human Rights Tracker available at https://rightstracker.org/en/country/NZL

An NHRI has a range of statutory powers which facilitate its monitoring activities. Firstly an NHRI will often have powers to request information from government departments and to interview government officials.[6] These powers can guarantee access to information necessary to determine if human rights violations have taken place.

A key challenge for human rights monitors is ensuring that their reports receive attention once they are published. The Paris Principles (1993) require that an NHRI be empowered to raise matters of concern with government. As such the designation of an NHRI as the dedicated mechanism ensures that monitoring reports relating to the CRPD receive appropriate government attention.

The designation of an NHRI also brings significant expertise to the monitoring of the CRPD. The expertise which an NHRI has can be placed into three categories; technical; policy; and process.

An NHRI and its staff have technical expertise in human rights law generally. As set out above, NHRIs are required to have as broad a mandate as possible. As a consequence, NHRIs have developed expertise in advising on and monitoring compliance with the full range of international and domestic human rights protections. The CRPD sits alongside other international treaties and domestic protections; monitoring compliance with the CRPD requires broad technical expertise in human rights law. NHRIs with broad expertise in domestic and international human rights standards are well positioned to monitor the implementation of the CRPD.

The development of policy and law reform measures which bring about the implementation of the CRPD is a complex task. Monitoring the development of reforms and their implementation will require extensive policy expertise (Waldschmidt, 2009, p. 9). Policy expertise refers to "knowledge of the range of policies and instruments, proposed and enacted, governing a particular policy area as well as knowledge of how they work" (Page, 2010, p. 271). The range of policies which impact on persons with disabilities is vast. There is a risk that "disability policy" will be defined restrictively to include only those social welfare and health policies designed specifically for persons with disabilities. NHRIs through their broad policy expertise can play a key role in ensuring the rights of persons with disabilities are mainstreamed throughout all relevant policies.

The third category of expertise which an NHRI brings can be classed as process expertise. Process expertise refers to "knowledge of the complex processes that have to be followed to ensure a proposal can be put into effect" (Page, 2010, p. 271). Through its role as an advisor of government and other state bodies on human rights compliance, an NHRI accumulates expertise on the processes of policy-making. The importance of human rights monitors being attentive to political priorities and bureaucratic cultures was recently acknowledged in a review of the impact of the office of the Special Rapporteur (Crowther & Priestley, 2020). NHRIs have extensive experience of presenting human rights in a credible way that resonates with domestic priorities and cultures. This expertise is valuable when developing

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[6] See, for example, the NI Human Rights Commission Northern Ireland Act 1998.

observations on the human rights situation and when developing plans for the implementation of recommendations emerging from the CRPD Committee.

Having now considered the specific features of an NHRI which make them suitable for inclusion in the monitoring framework, we will now consider how monitoring frameworks have been developed in practice.

Monitoring Frameworks Not Including NHRIs

Where frameworks have been developed without the inclusion of an NHRI, these have been shown to lack resources, capacity, and most significantly the independence required to perform their duties effectively (CRPD Committee, 2012, 2016a, 2018a; Ferrajolo, 2017; Tabaj & Uršič, 2013). In the case of Kenya, the Committee expressed concern that the framework did not comply with the Paris Principles and specifically recommended that the Kenya National Commission on Human Rights be included to address this (CRPD Committee, 2015b). Similarly the Committee found that the designation of a Chief Commissioner for Persons with Disabilities along with state commissioners as the Indian independent mechanism was insufficient to guarantee independence and recommended the inclusion of the NHRI within the framework (CRPD Committee, 2019f, para. 69).

Austria initially established an independent framework composed of a monitoring committee under the Federal Disability Council, which was responsible for advising the Minister for Social Affairs. While the monitoring committee included a strong representative from civil society, when the CRPD Committee examined Austria, it raised concerns about the lack of independence of the monitoring committee and the absence of a designated budget. The Committee recommended that it should be brought into compliance with the Paris Principles (CRPD Committee, 2019a). Noting these concerns, the Austrian Government has developed new regulations to guarantee the independence and a budget for the Independent Monitoring Committee in 2018 (Austrian Monitoring Body, 2018, p. 30). As Austria is undergoing the second cycle of country review, whether the Committee is satisfied with this adjustment and the framework's compliance to Article 33(2) is yet to be known.[7]

In Spain the Spanish Committee of Representatives of Persons with Disabilities was initially solely designated as the independent monitoring framework. However in light of concerns relating to the lack of statutory powers, the Spanish Government included the Spanish A status NHRI within the monitoring framework (The Center for Disability Law and Policy, 2016, p. 22).

Overall it appears that independent monitoring frameworks which do not include an NHRI have been found to be inadequate by the CRPD Committee. Frameworks designed around OPDs, state bodies with thematic responsibility for disability, and even bespoke bodies have not proven to be effective or compliant with Article 33(2).

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[7] There is no question on Article 33 in the list of issues prior to submission of the combined second and third periodic reports of Austria. See UN Doc CRPD/C/AUT/QPR/2–3.

Monitoring Frameworks Composed of NHRIs and OPDs

While it was initially presumed that states would include OPDs within the independent monitoring framework, in reality there are limited examples of this in practice (De Beco & Hoefmans, 2013, p. 30). There are two examples known to the authors of frameworks in which an NHRI has been designated alongside an OPD, which we will now consider.

The New Zealand Human Rights Commission is designated as the independent mechanism alongside the Ombudsman, who handles complaints, and the Disabled People's Organizations' Coalition, a body composed of representatives from seven OPDs. Reflecting its new role, the composition of the New Zealand Human Rights Commission was reformed to include a designated disability commissioner. Commissioners are appointed by the New Zealand Government but can be nominated by interest groups such as OPDs (Ministry of Justice New Zealand Government, 2020).

The New Zealand Independent Mechanism operates as one entity in how it goes about engagement and in the production of reports.[8] The Mechanism meets twice yearly with relevant Ministers to share its views and press for change. However, it noted, "engagement does not necessarily translate to commitments to integrate accommodation and inclusion meaningfully, or to make the large-scale shifts in systems-level policy required in education, justice, housing or employment" (Independent Monitoring Mechanism NZ, 2020).

New Zealand was examined by the CRPD Committee in 2014, and the Committee commended New Zealand for establishing a framework in compliance with Article 33(2). However, the framework itself notes that there is room for improvement. In a recent report, the Mechanism noted that it does "not always have as diverse representation as that envisaged by General Comment 7" (Independent Monitoring Mechanism NZ, 2020).

In Spain, the independent framework is composed of an OPD, the Spanish Committee of Representatives of Persons with Disabilities, and the Spanish NHRI. The Spanish Committee is an umbrella organization representing over 600 organizations (The Center for Disability Law and Policy, 2016, p. 22). In its initial examination of Spain, the CRPD Committee recorded that Spain was "in full compliance with Article 33(2)" (CRPD Committee, 2019c, para. 6). Reflecting the importance of state resourcing, a subsequent review of Spain in 2019 recommended that the State Party "strengthen the capacity of the Spanish Committee of Representatives of Persons with Disabilities" (CRPD Committee, 2019c).

In a research report to inform the development of the independent mechanism in Ireland, the NUIG Center for Disability Law and Policy noted that the Spanish framework was an attractive model. However, they acknowledged that few states hosted an umbrella OPD analogous to the Spanish Committee of Representatives (The Center for Disability Law and Policy, 2016). In light of the emphasis which the CRPD Committee have placed on the establishment of an umbrella organization, this

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[8] See https://www.hrc.co.nz/our-work/people-disabilities/making-disability-rights-real/.

may lead to a growth in their number, potentially facilitating the adoption of similar models.

Monitoring Frameworks Including NHRIs Alongside Other Statutory Bodies

A number of states have designated an NHRI alongside other relevant public authorities.

The Danish Government designated the Danish Institute for Human Rights, the Danish Disability Council, and the Danish Parliamentary Ombudsman as the independent framework.[9] The Danish Institute, in line with the Paris Principles, is responsible for protecting, promoting, and monitoring the Convention. The Parliamentary Ombudsman is the national equality body, principally handling complaints. The Danish Disability Council is a 17-person council composed of representatives of government bodies and civil society organizations including 5 OPDs (CRPD Committee, 2014b, para. 383). The Danish Disability Council has specific responsibility for "discussing and assessing developments in society for persons with disabilities" (CRPD Committee, 2014b, para. 383). The Council, therefore, provides a link with OPDs to allow the lived experience of persons with disabilities. In addition to these arrangements, the founding statute of the Danish Institute was amended to provide for its board to include a member nominated by OPDs.

Monitoring Frameworks Solely Designated NHRIs

As set out above, the CRPD Committee have been broadly content for NHRIs to be solely designated as the independent mechanism. In recent examinations, the Committee have considered in more detail how an NHRI is including persons with disabilities in its monitoring activities. In its concluding observations on the Philippines, the Committee specifically raised concerns at the, "lack of specific mechanisms within the Commission on Human Rights of the Philippines to engage and ensure the participation of persons with disabilities, through their representative organizations, in monitoring the Convention at the national and local levels" (CRPD Committee, 2018b).

NHRIs who have been designated more recently as independent mechanisms have tended to give detailed consideration to the inclusion of persons with disabilities within their structures (The Center for Disability Law and Policy, 2016). Upon ratification of the CRPD, the Irish Government indicated that it would designate its NHRI the Irish Human Rights and Equality Commission as its independent mechanism. In anticipation of this, the Commission have established a Disability Advisory Committee or DAC to advise the Commission on its role as the independent

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[9] Parliamentary Decision B 15 of 17 December 2010

monitoring framework. The members of the DAC were appointed following an open recruitment process and are appointed on an individual basis (Irish Human Rights and Equality Commission, 2019). While many members of the DAC are involved in or employed by OPDs, they are appointed in their individual capacity rather than to represent the views of particular organizations. Ireland has not yet been examined by the CRPD Committee.

In Australia, the Australian Human Rights Commission or AHRC, which is also the national equality body, is solely designated as the independent monitoring framework. The AHRC reflects the Commission model of a NHRI (Australian Human Rights Commission, 2020). The AHRC is led by a Chief Commissioner along with seven Commissioners. Each Commissioner has a specific remit, including a Disability Discrimination Commissioner.

The Disability Discrimination Commissioner is appointed by the government. The Disability Commissioner engages in national consultations with persons with disabilities and draws on their expertise by way of a number of expert reference groups on specific projects (CRPD Committee, 2019a, para. 111). Despite these efforts in a shadow report to the CRPD Committee in advance of the second examination of Australia, the OPD Disability Rights Now expressed concern at the lack of formal engagement mechanisms within the AHRC to engage with OPDs (Disabled People's Organizations Australia, 2017). In its concluding observations, the CRPD Committee recalled these concerns and recommended the State Party "establish a formal mechanism and ensure sustainable and adequate funding for the meaningful engagement of persons with disabilities and their representative organizations in the implementation and monitoring of the Convention" (CRPD Committee, 2019a, para. 62).

This recommendation reflects the emphasis which the CRPD Committee place on the involvement of persons with disabilities through their representative groups, who will reflect the diversity of views of persons with disabilities. It appears that the inclusion of persons with disabilities on advisory boards or even within decision-making bodies will be insufficient to meet the requirements of Article 33(2).

Since the publication of General Comment No. 7, a number of NHRIs solely designated as an independent mechanism have revised their internal arrangements for engaging with persons with disabilities and their representative groups, for instance, the Northern Ireland Human Rights Commission or NIHRC, which is jointly designated with the national equality body as the independent mechanism for Northern Ireland. Following the publication of the General Comment No. 7, the NIHRC has proposed the development of a disability forum. The forum will be composed of OPDs, civil society organizations, and persons with disabilities. The forum will advise the independent mechanism on its work providing insight into the lived experience of persons with disabilities.[10] In determining the composition of OPDs and civil society organizations to be represented on the forum, the NIHRC

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[10] Independent Mechanism for NI, IMNI Disability Forum

must ensure the selected members are reflective of all persons with disabilities in Northern Ireland.

The South African NHRI has both a Commissioner specifically responsible for disability and an advisory committee on disability issues.[11] The advisory committee includes both civil society organizations and individual experts who advise the Commission. The composition of an advisory committee is determined at the discretion of the South African NHRI. OPDs have raised concerns that their views have not been taken into consideration by the South African NHRI (CRPD Committee, 2011; Mahomed et al., 2019, p. 356). The designation of the South African NHRI as the Independent Mechanism has not yet taken place (South African Human Rights Commission, 2020).

As set out above, many NHRIs have been designated as the independent mechanism without amendments being made to their legal mandate. Of the examples discussed only in Denmark, do we see the state adjusting the composition of the NHRI to provide for the inclusion of an additional member of their governing body, to be nominated by OPDs. In the absence of states amending or reviewing the NHRIs mandate to ensure its suitability for the role of an independent mechanism, the onus is placed on the NHRI itself to consider how it includes persons with disabilities and their representative groups in its activities.

Quinn and Crowther (2017) highlight that, "Some NHRIs have expressed concern about the impact of involving persons with disabilities on their 'de facto' independence as required by the Paris Principles." While it is accepted that the independence of an NHRI can be encroached by civil society organizations just as it can by state bodies, through careful management, such risks can be addressed (Aichele, 2018).[12] Indeed in addition to requiring that NHRIs are independent, the Paris Principles require that they be pluralistic. To be effective NHRIs must be pluralistic and reflect prevailing social forces in society, including CSOs. The Paris Principles (1994, para.3) acknowledge "the fundamental role played by the non-governmental organizations." The SCA suggest that pluralism can be guaranteed in a number of ways including through procedural mechanisms such as advisory committees, networks, or public forums. The SCA recommends that NHRIs develop constructive and systematic working relationships with NGOs and other bodies. It further suggests that these relationships be formalized through "public memoranda of understanding" (GANHRI, 2017, p. 11). The involvement of OPDs within an advisory committee or a formal mechanism established by an NHRI is therefore in fact recommended by the SCA and rather than impinging upon the independence of the NHRI should instead strengthen its capacity.

The inclusion of civil society and OPDs can significantly strengthen the capacity of an NHRI to perform its role as the independent monitoring mechanism.

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[11] See https://www.sahrc.org.za/index.php/focus-areas/disability-older-persons

[12] Aichele has highlighted that for NHRIs, *the principle of independence requires equidistance from the state and any civil forces.*

Effective Collaboration Between Independent Monitoring Frameworks and Civil Society Organizations

Collaboration between NHRIs and OPDs in monitoring the implementation of the CRPD can be mutually reinforcing. Now, we will consider what opportunities the designation of an NHRI as an independent mechanism opens up to OPDs. We will set out four opportunities which the designation of an NHRI as an independent mechanism presents to OPDs.

Collection of Data

The OHCHR identifies one of the five purposes of monitoring to be the creation of new partnerships (OHCHR, 2012b, p. 19). In addition to developing its own independent monitoring activities, a key role for an independent monitoring mechanism is to develop new partnerships between the state and civil society in developing monitoring data systems to inform and track implementation.

For the first time in a human rights treaty, the CRPD in Article 31 requires that "states parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention."

When formulating Article 31, negotiators suggested that a reference to data collection be included within Article 33 (UN Enable, 2004). While this proposal was not adopted, it continues to be acknowledged that robust data collection is essential both for effective policy-making and effective monitoring by the independent mechanism. As Pederson has highlighted, "the work of the monitoring bodies in assessing implementation through the use of statistics and research data depends in large on the quality of the data collected by states parties" (Pedersen & Ferretti, 2018).

The development of Article 31 was influenced by the need to reform data collection systems which tended to focus on the measurement of impairment rather than the identification and measurement of disabling barriers (Lawson & Priestly, 2015). States need to develop data collection processes which identify previously hidden impediments to the full participation of persons with disabilities in society.

The CRPD Committee and disability advocates emphasize the importance of including OPDs and their accounts of the lived experience of persons with disabilities within processes of knowledge production (Boucher & Fiset, 2015, p. 128). In contrast to this approach, states have increasingly moved toward evidence-based policy-making processes. Such processes tend to privilege objective evidence which is scientifically rigorous over lived experience or experiential knowledge (Smith-Merry, 2020, pp. 305–316).

Disability advocates emphasize the need to develop emancipatory processes of evidence production through the establishment of workable dialogue between persons with disabilities and those responsible for research (Barnes, 1992, p. 122). NHRIs can play a key role in working with state entities to develop facilities for persons with disabilities and their representative groups to provide inputs to data collection processes (Priestley & Lawson, 2014, p. 752).

The use of indicators has taken on significant prominence in monitoring the implementation of human rights instruments. Eilionoir Flynn has highlighted that, “. . .the CRPD implicitly requires the development of future indicators and sets the contours for measuring success in improving the lives of persons with disabilities” (Flynn, 2011, p. 34). While the use of indicators is seen as a positive development in human rights monitoring, there are certain risks (OHCHR, 2012a).

Indicators frame problems and if the process for their development is not robust and inclusive, they may be manipulated by states to present narratives of success (Davis et al., 2012, p. 71). NHRIs and OPDs must work together to ensure indicators satisfy standards of validity while reflecting the principles of the CRPD (OHCHR, 2012a). The OHCHR has developed a holistic set of indicators linked to the CRPD articles, which provide a basis on which to develop indicators specific to their jurisdiction which can be integrated into domestic instruments.[13]

The development of a monitoring strategy based on indicators can often privilege those with technical expertise over those with lived experience (Brunsson & Jacobsson, 2002, p. 46). NHRIs can play a role in advising the state on the need to develop facilities to allow persons with disabilities to provide insight from their lived experience (Berghs et al., 2016, p. 35). NHRIs can also play a role in assisting OPDs to frame the evidence gathered from their lived experience to ensure it is credible and relevant to the process of applying indicators.

Monitoring CRPD Recommendations

The CRPD Committee’s Guidelines on independent mechanisms emphasize a key role for an independent mechanism in monitoring the implementation of the recommendations of the CRPD Committee (CRPD Committee, 2016b, para. 21). Discussion on UN treaty reform has highlighted how NHRIs can play a key role in the “domestication of treaty body outputs” (Egan, 2013, p. 664). NHRIs have developed innovative tools for tracking the implementation of treaty body recommendations (FRA, 2020).

As the CRPD Committee recommendations are rarely put forward in an implementable form, it is necessary for an NHRI to play a key role in “thickening” the standards and recommendations to ensure they have resonance in the domestic context (Soohoo & Stolz, 2008, p. 495). Human rights commentators highlight the need for processes of vernacularization, “by which transnational human rights are adapted to local contexts” (Merry, 2009, p. 211). The first task of monitoring treaty body recommendations is therefore the development of a domestic plan for implementation. The participation of OPDs in the decision-making processes of such domestic plans should be ensured. The CRPD Committee encourage states to first adopt “legal and regulatory frameworks and procedures to ensure the full and equal involvement” of OPDs (CRPD

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[13] Available at https://www.ohchr.org/EN/Issues/Disability/Pages/sdg-crpd-resource.aspx

Committee, 2018d, para. 53) (CRPD Committee, 2018d, para. 53) (CRPD Committee, 2018d, para. 53) (CRPD Committee, 2018d, para. 53).

During the negotiation of the CRPD, the Australian NHRI proposed the incorporation of an obligation on Member States to develop a National Disability Action Plan or NDAP on implementation of the CRPD (Stein & Lord, 2010, pp. 702–703). While this proposal was not adopted, interest in the utility of NDAPs remains (Stein & Lord, 2010, pp. 702–703). Jerome Bickenbach (2011) highlights that to be effective rights must be *operationalizable* into policy goals, which should then be broken down into *challenging yet feasible* targets. An NHRI which has accumulated knowledge of how government works and political perceptiveness is uniquely placed to propose or scrutinize implementation plans which are challenging yet feasible (Mintrom, 2007, p. 146). The New Zealand NHRI has played a key role in developing New Zealand's National Action Plan, a plan consisting of 100 actions, supported by 232 indicators to effect the implementation of recommendations from the international human rights system including the CRPD Committee.[14] Thanks to the participation and collaboration of Disabled People's Organisation Coalition in New Zealand with government, the newest Disability Action Plan 2019–2023 responds to issues raised by the disability community.[15]

Developing New Analytical Approaches

Ensuring that a state's data collection systems provides an accurate reflection of the lives of persons with disabilities is central to ensuring the effective implementation of the CRPD. Through their advisory role, NHRIs can challenge government approaches to statistical analysis to ensure they are presenting an accurate reflection of the lived experience of persons with disabilities.

In the UK, austerity measures were considered to have disproportionately impacted on persons with disabilities. However due to the state's silo approach to data collection, the full impact of austerity measures on the lived experience of persons with disabilities was not being captured (Roberts et al., 2017, pp. 167–184). Noting this the UK's Equality and Human Rights Commission developed a methodology for conducting Cumulative Impact Assessment or CIAs to assess the impact of social security and tax reforms on the household incomes of individuals.[16] Such assessments would provide a more accurate record of the impact of the totality of austerity measures on the lives of persons with disabilities.

The Commission has advocated that the UK Government integrate CIAs into their own monitoring activities. On examining the UK, the CRPD Committee recommended that the UK Government conduct CIAs in relation to the impact of

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[14] See https://npa.hrc.co.nz/overview

[15] See https://www.odi.govt.nz/disability-action-plan-2/

[16] See https://www.equalityhumanrights.com/en/publication-download/cumulative-impact-tax-and-welfare-reforms

social security reforms in the UK and integrate the methodology into policy development processes (CRPD Committee, 2017c). The adoption of this methodology would significantly strengthen the capacity of OPDs to analyze the impact of proposed policy measures.

Independent Investigation

While often associated with the protection remit of an NHRI, the systemic investigation of human rights issues can form part of NHRI's monitoring plans. Such investigations can be used to mitigate the failure of state monitoring activities to fully capture the lived experience of persons with disabilities. For instance, the National Human Rights Commission of Mexico conducted an investigation into the accessibility status of certain government facilities which demonstrated the failure of government monitoring activities to identify and address obstacles to accessing buildings and services.[17]

For those states where NHRIs are assigned the investigation role, OPDs could participate through several means, including submission of complaints, provision of support to applicants, and submitting evidence to NHRIs when conducting an investigation.

Conclusion

The innovation of establishing the independent monitoring framework at the domestic level is still in a process of discovery. The publication by the CRPD Committee of General Comment No. 7 has led to an increased focus on how persons with disabilities and their representative groups are being included within independent frameworks. The reluctance by State Parties to develop frameworks which include OPDs has placed the onus on NHRIs to review their internal structures. While NHRIs face resourcing issues and have concerns relating to independence, these are not insurmountable. The CRPD Committee have clearly demonstrated a need for independent mechanisms to develop formal procedures of engagement with persons with disabilities and OPDs. While a number of NHRIs have developed advisory committees, these have tended to include persons with disabilities as individuals rather than as representatives of organizations of persons with disabilities. The CRPD Committee clearly see the value of OPDs participating in the activities of the monitoring framework (CRPD Committee, 2018d). There is clearly a need for NHRIs designated as an independent mechanism to establish formal procedures of engagement with OPDs. Through such procedures, NHRIs can share their expertise

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[17] See http://tbinternet.ohchr.org/_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935 &Lang = en.

and insights with OPDs and strengthen the development of domestic disability movements.

Further research is required to identify how effective collaboration between NHRIs and OPDs can achieve advancements in the rights of persons with disabilities which would not have been achievable otherwise. We believe that experience to date has shown that the key to this lies in the triangular relationship of civil society, NHRIs, and the state. NHRIs can play a key role in collaborating with OPDs in ensuring the lived experience of persons with disabilities is presented to governments in a way that is impactful. The credible evidence which it generates can facilitate the initiation of a program of law reform to implement the CRPD. Delivering this reform requires collaboration, long-term commitment, and patience from all actors.

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Bridging the Gap: Harnessing the Synergies Between the CRPD and the SDG Monitoring Frameworks

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Contents

Abstract

Since the adoption of the Convention on the Rights of Persons with Disabilities (CRPD), the recognition and advancement of the rights of persons with disabilities at the international level has grown exponentially, thanks to the work of the Committee on the Rights of Persons with Disabilities (CRPD Committee) and other stakeholders. The rise of the disability agenda is also reflected in the 2030

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Agenda for Sustainable Development that includes explicit references to persons with disabilities, including in its indicators framework, meaning that action taken for persons with disabilities should be tracked, measured, and reported on to the High-level Political Forum (HLPF) on Sustainable Development. The SDG-CRPD resource package, recently launched by the Office of the United Nations High Commissioner for Human Rights (OHCHR), came to offer additional guidance to promote SDGs implementation under the CRPD. Against this background, the purpose of this chapter is to explore the complementarity of the monitoring frameworks of the CRPD and SDGs, and how to harness those synergies to advance the rights of persons with disabilities. To do so, the chapter compares CRPD- and SDG-based frameworks and processes for monitoring and explores the SDG-CRPD resource package developed within the EU-funded project, Bridging the Gap I, offering tools to ensure that all actions for the SDGs are inclusive of persons with disabilities and informed by the CRPD, including human rights indicators on the CRPD and data sources guidance to guide data collection and monitoring efforts.

Introduction

Over 15 years have passed since the adoption of the Convention on the Rights of Persons with Disabilities (CRPD), one of the latest human rights treaties adopted at the United Nations. The Convention enshrines a paradigm shift from outdated perspectives to the human rights model of disability which considers persons with disabilities first and foremost as rights holders. Its convening power is evident; with 185 States Parties, the Convention has achieved near-universal ratification. Considered as both a human rights instrument and a development tool, the Convention spells out the importance of international cooperation and partnerships with international and regional organizations and civil society, particularly organisations of persons with disabilities (OPDs), to support national efforts to realize its principles and provisions. The CRPD Committee, through its reviews, individual communications, and general comments, has elaborated on key standards of inclusive equality as it applies to equal recognition before the law, education, participation, and living independently and being included in the community, among other rights.

Since the adoption of the CRPD, the recognition, awareness, and advancement of the rights of persons with disabilities at the international level have grown exponentially. This is in large part thanks to the work of the Committee on the Rights of Persons with Disabilities (CRPD Committee) which has been central to the unfolding and understanding of the standards of the Convention. Additionally, multiple stakeholders, among others, States, the UN Special Rapporteur on the Rights of Persons with Disabilities, UN entities, development actors, and a very active disability movement have contributed to mobilizing and dynamizing the discourse and practice on the rights of persons with disabilities. The adoption of the United Nations Disability Inclusion Strategy (United Nations, 2019) exemplifies and embodies this mobilization and momentum: as coined by the former Special Rapporteur on the Rights of Persons with Disabilities, the UNDIS represents “the operationalization of the CRPD for the UN,” calling for disability inclusion across the UN system from HQ to the field, throughout its policies, procedures, and programming.

The rise of the disability agenda is also reflected in the 2030 Agenda for Sustainable Development which was adopted in 2015 and puts forward 17 Goals and 169 targets (United Nations, 2015). Its adoption marks a turning point for persons with disabilities. Having been overlooked by its predecessor, the Millennium Development Goals (MDGs), and thereby excluded from the gains achieved, the disability community was mobilized not to once again be left behind. Equipped with the CRPD and the lessons acquired through its negotiations, organizations of persons with disabilities (OPDs) achieved the inclusion of persons with disabilities in the 2030 Agenda, not only through explicit references across several Goals but also more broadly due to the fact that the SDGs are grounded in human rights and adopt a people-focused approach. Moreover, the SDGs refer to persons with disabilities in their indicators framework, meaning that action taken for persons with disabilities should be tracked, measured, and reported on to the High-Level Political Forum (HLPF) on Sustainable Development.

Strengthening the complementarity of the monitoring frameworks of the CRPD and SDGs is central to their mutual success and the overall inclusion and participation of persons with disabilities. Despite significant strides to enhance disability inclusion in the global agenda, further guidance and action are needed to effectively reach persons with disabilities, who remain among the furthest left behind. The SDG-CRPD resource package, launched by the Office of the United Nations High Commissioner for Human Rights (OHCHR), offers such guidance, in particular through the application of human rights indicators on the CRPD that contribute to converge monitoring of the CRPD and SDGs.

Against this background, the purpose of this chapter is to explore the complementarity of the monitoring frameworks of the CRPD and SDGs and how to harness those synergies to advance the rights of persons with disabilities. Section “The CRPD and SDG Monitoring Frameworks” of this chapter addresses and compares CRPD- and SDG-based frameworks and processes for monitoring, while section “Bridging the Gap: OHCHR’s SDG-CRPD Resource Package” explores the SDG-CRPD resource package developed within the EU-funded project, Bridging the Gap I, offering tools to ensure that all actions for the SDGs are inclusive of persons with disabilities and informed by the CRPD, including human rights indicators on the CRPD and data sources guidance to guide data collection and monitoring efforts.

The CRPD and SDG Monitoring Frameworks

The Importance of Monitoring and Data

Monitoring of human rights instruments and political commitments is an indispensable step toward their realization. In essence, monitoring seeks to verify whether States are fulfilling their obligations and whether individuals are enjoying their rights in practice; in doing so, it unveils a host of information on how, where, when, and whom, information which serves to improve actions and identify gaps to be addressed for continued and strengthened implementation. Actions entail all possible efforts that contribute to realizing rights and commitments, be it legal reform, policies, programs, resource allocation and investments, awareness-raising, training, information dissemination, consultations, or data collection. As such, monitoring serves as a mechanism to identify rights violations, as well as to detect shortcomings and delays in implementation with the overall aim of fostering accountability and enforcement of human rights obligations.

Monitoring can take many forms and can be conducted by any individual or body interested in tracking progress and upholding accountability. This includes everyone from the government itself to NHRIs, civil society, development actors, donors, and regional and international bodies overseeing development and human rights. Monitoring includes gathering testimonies and case studies of individuals' lived experiences that attest to the exercise of rights in practice; this is pertinent not only in relation to human rights instruments but also to gauge the progress of people-centered commitments such as the SDGs. Hence, the participation of civil society organizations (CSOs), including organizations of persons with disabilities, is a key component to monitoring processes and has been so recognized by the CRPD and the SDGs.

Data is also a vital element to monitoring – both qualitative and quantitative data. Data collection and disaggregation are enshrined in the CRPD and SDGs in recognition of their capacity to measure progress over time and enable assessment of progress as it concerns the diversity of individuals and populations. Indicators are increasingly playing a part in monitoring by putting forward measures capable of determining the fulfilment of the normative content of rights or commitments.

The CRPD and SDG frameworks provide for their monitoring through their call to institutionalize data collection and disaggregation, thus assuring the generation of information necessary to engage in monitoring. Further, monitoring obligations call for putting structures and processes in place at the national level to facilitate measuring and tracking advances, thereby driving implementation forward. And periodic reviews at the global level create further impetus for implementation.

Monitoring of the CRPD

The drafting of the CRPD benefitted from the experience of decades of monitoring of previous human rights treaties and the lessons learned through those processes. Furthermore, CRPD drafting itself involved an unprecedented level of participation by civil society, determined to secure measures to facilitate and strengthen the Convention's fulfilment in practice. Consequently, the CRPD encompasses innovative provisions including on monitoring the rights of persons with disabilities. The framework includes a combination of national and international monitoring mechanisms that highlight the participation of organizations of persons with disabilities.

Obligation to Collect and Disaggregate Data

Article 31 of the CRPD requires States to "collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention," in accordance with data protection standards and ethical principles from statistics (paragraph 1). The information should be "disaggregated, as appropriate, and *used to help assess the implementation* of States Parties' obligations" (emphasis added) and duly disseminated ensuring accessibility to persons with disabilities (paragraphs 2 and 3). In this sense, States need to ensure that their data collection efforts – carried out by the national statistics offices (NSOs) and public authorities – consider explicitly the variable of disability (e.g., through national censuses, administrative data gathered by sectoral authorities, survey data, etc.).

Data disaggregation by disability, in particular statistical data, remains a complex and technical challenge which requires continuous development and improvement to ensure the quality and employability of data, as well as increased representation of the diverse constituencies among the population of persons with disabilities. Throughout the last years, the CRPD Committee has recommended the use of the tools developed by the Washington Group on Disability Statistics, notably the Short Set of Questions on Disability for national censuses and surveys (UNCRPD Committee, 2019a, 2019b, 2019c, 2019d; UNCRPD Committee & GANHRI, 2018). Disaggregation is one component of a human rights-based approach to data collection, along with participation, self-identification, transparency, privacy, and accountability (UNOHCHR, 2018). These principles are central to improving the quality, relevance, and use of data and statistics in accordance with international human rights.

Monitoring Mechanisms Under the CRPD

The CRPD foresaw the need for strong and institutionalized national monitoring practices encompassing not only data collection and disaggregation by disability but also national and international monitoring mechanisms. At the national level, the CRPD calls for designating one or more independent mechanisms in charge of monitoring implementation and the involvement of civil society, including the right holders, persons with disabilities.

Article 33(2) of the Convention mandates States to put in place national independent monitoring mechanisms. It provides:

> States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention.

In practice, this function usually falls on existing national human rights institutions (NHRIs), which should comply with the Principles relating to the status and functioning of national institutions for protection and promotion of human rights (or "Paris Principles"). In this way, the CRPD envisions the existence of one or more permanent independent mechanism(s) with budgetary and technical resources to closely monitor the implementation of the CRPD. Through country reviews, the CRPD Committee has consistently called for the appointment of the independent monitoring mechanism and the allocation of sufficient budgetary resources for their effective functioning (UNCRPD Committee, 2015, 2017a, 2017b, 2018a).

Furthermore, Article 33(3) of the CRPD requires that "[c]ivil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process." The CRPD Committee has stressed on the obligations of States to support, including with budgetary resources, the development of technical capacities to enable the meaningful participation of organizations of persons with disabilities (UNCRPD Committee, 2018b).

The work of the independent monitoring framework at the national level contributes to the role of international monitoring under the mandate of the CRPD Committee. The principal monitoring activity of the CRPD Committee is undertaken through review of State Parties' compliance with the CRPD carried out through its periodic reporting framework. States Parties to the CRPD submit their initial report, which provides information on the situation of persons with disabilities as it relates to Articles 1 to 33 of the CRPD and what measures have been undertaken to enhance the enjoyment of their rights as enshrined therein. Once the country figures on the Committee's agenda of work, it will adopt a List of Issues directed to the State that comprises questions for clarification and requests for additional information to complement the initial State report. States should present their Reply to the List of Issues ahead of the scheduled exchange. The Committee and the State prepare for the "constructive dialogue" comprising 6 hours of discussion covering Articles 1 to 33 of the CRPD, following which the Committee will adopt its Concluding Observations, i.e., recommendations directed to the State to better implement and meet the obligations of the CRPD.

The CRPD Committee puts significant weight on the participation of OPDs and civil society in this process and welcomes alternative information and testimonies by persons with disabilities which serve to cast light on lived experiences and the reality on the ground. At each stage of the review process, OPDs and other CSOs have the opportunity to provide information in writing, through comprehensive alternative reports or briefs which include responses to and alternate versions of information provided by the State (UNCRPD Committee, 2014). There are both official and informal spaces for private briefings with the Committee. Formal briefings usually last between 1 hour and 1.5 hours and take place prior to the adoption of List of Issues, as well as just before the commencement of the constructive dialogue between the Committee and the State. Informal meetings with Committee members, in particular the member appointed as country rapporteur who is tasked to lead the dialogue with that State, can also take place on the sidelines of the Committee's session and allow for more in-depth discussion, including updates and clarifications on any of the information officially submitted. These informal meetings are held at the discretion of members and are dependent on their availability and interest. It is commendable that, since it began engaging in constructive dialogues in 2011, Committee members have consistently made efforts to be available to OPDs and

CSOs to learn from their concerns and experiences. National OPDs have welcomed the CRPD Committee's Concluding Observations as valuable tools for their national advocacy.

Monitoring of the SDGs

The experience of the Millennium Development Goals (MDGs) underscored the need for a sound indicator framework and corresponding monitoring systems to effectively measure progress toward achieving the SDGs. Therefore, the 17 Sustainable Development Goals and its 169 related targets have been designed to be monitored through a set of global indicators. Progress on indicators informs the High-Level Political Forum (HLPF), the principal platform on sustainable development that oversees the follow-up and review of the implementation of the agenda at the international level, including through the state-driven Voluntary National Reviews.

Sustainable Development Goals: Data-Specific Targets and SDG Indicators Framework

Within the SDG framework, there are two main elements which drive monitoring. First, the 2030 Agenda includes specific targets calling for data collection and disaggregation. Second, the Inter-Agency and Expert Group on SDG Indicators (IAEG-SDGs) developed a global indicator framework, adopted in 2017.

Given the need to improve national data systems to produce quality data to assess progress of its implementation, Sustainable Development Goal 17 "Strengthen the means of implementation and revitalize the Global Partnership for Sustainable Development" includes a sub-section on "Data, monitoring and accountability." Within that, Target 17.18 stresses the need to enhance capacity-building support to developing countries "to increase significantly the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, *disability*, geographic location and other characteristics relevant in national contexts." Target 17.19 calls for building on initiatives to "develop measurements of progress on sustainable development that complement gross domestic product." Both targets clearly lay out the need for States to strengthen their systems for data collection and disaggregation in order to better track and better know the situation of people and how different groups are faring, aligning fully with the overarching objective of the 2030 Agenda to leave no one behind. At the 2016 HLPF, several countries acknowledged the need for improved quality of data collection and disaggregation to measure progress and pointed out to the human resource and financial constraints and the challenges to produce data at the local levels (UNDESA, 2016).

The UN Statistical Commission created the Inter-Agency and Expert Group on SDG Indicators to develop a proposal for a "Global indicator framework for the Sustainable Development Goals." In March 2017, the UN Statistical Commission adopted a global indicator framework, which was subsequently endorsed by the

General Assembly on 6 July 2017 (United Nations, 2017). The global indicator framework includes 231 unique indicators, linked to the 169 targets. Posterior refinements, deletions, and additions to the framework have taken place, and the framework will continue to be adapted. The metadata for the SDG indicators have been developed, which put forward the technical information and methods underlying measurement of the indicators (e.g., concepts and definitions, rationale, computation method, etc.). In addition, alternative or complementary indicators for national and subnational levels of monitoring can be developed on the basis of national priorities, realities, capacities, and circumstances (UN Statistical Commission, 2020). The global indicator framework entails four levels of monitoring for the SDGs: national, regional, global, and thematic (Sustainable Development Solutions Network, 2015). Data drawn from these processes, including through the work of "custodian agencies" (UN entities or international organizations responsible for collecting data from countries under existing mandates and reporting mechanisms), is transmitted and compiled, extending to the annual SDG progress report that, in turn, serves to inform the HLPF and highlight matters requiring attention (United Nations, 2016; UN Secretary General, 2016).

SDG International Monitoring Processes: Voluntary National Reviews

Besides monitoring based on the global indicator framework, the core element for follow-up and review on the implementation of the SDGs is through the Voluntary National Review (VNR). The VNR is a process through which countries assess their progress in realizing the SDGs and share their challenges and experiences. Member states are encouraged to "conduct regular and inclusive reviews of progress at the national and subnational levels, which are country-led and country-driven" (United Nations, 2015). Consultations at the national and regional levels feed into the global VNR and are thus important opportunities for civil society organizations, including OPDs, to voice their concerns (Lockwood, n.d.).

Every year, a group of VNRs is presented at the HLPF during the 3-day ministerial segment during the 3-day ministerial segment. In 2022, 45 counriest will be subject to the VNR. States undergoing a first-time review are allocated 30 minutes, and those undergoing a subsequent review are allocated 20 minutes and often are grouped with other countries. Even though the review is voluntary, there is considerable political peer pressure for countries to undertake their review as a display of their commitment to the SDGs. Each year, an overarching theme is selected for the HLPF, linked to specific Goals, and which may figure in the VNR, alongside review of all 17 SDGs. For example, the designated theme for 2022 is "Building back better from the coronavirus disease (COVID-19) while advancing the full implementation of the 2030 Agenda for Sustainable Development." This theme is to be accompanied by in-depth review of Goals as wide and varying as Goals 4 on quality education, 5 on gender equality, 14 on life below water, 15 on life on land, and 17 on partnerships for the Goals (United Nations 2021). The limited time and plurality of topics for review leave it very much to the State to shape the focus of the VNR discussions.

Civil society organizations can participate at the local and national level in the lead up to the HLPF in national consultations, as well as in regional consultations. One of the most important opportunities for CSOs to engage in the VNR process is through national consultations organized by governments. At the HLPF, CSOs can participate exclusively through the "Major Groups and other Stakeholders," which includes the Stakeholder Group of Persons with Disabilities. The Stakeholder Group of Persons with Disabilities aims to "enhance the opportunity for persons with disabilities, their representative organizations, and non-governmental and other organizations working on the rights of persons with disabilities to advocate with a unified voice for their inclusion in all sustainable development related UN processes" (Stakeholder Group of Persons with Disabilities, 2017) including putting forward issues related to persons with disabilities in the VNR. Stakeholders have the opportunity to deliver one statement per country raising issues and posing questions, which implies the need for all CSOs and stakeholders to coordinate, prioritize, and agree on the topics to be addressed. Other States are also able to put forward questions. Finally, there is no formal mechanism or structure for follow-up of the VNR. However, subsequent VNR reports can provide a summary of initiatives and actions rolled out since the previous review, including challenges overcome and lessons learned.

Differences and Synergies of CRPD and SDG Reporting Processes: Opportunities and Threats (Table 1)

The reviews by the CRPD Committee and the VNR at the HLPF represent distinct processes with distinct purposes, and their comparison would liken that between apples and oranges. The table below exposes the complementarity between the CRPD review and the VNRs. What is common to both is that their respective success depends on each other and organizations of persons with disabilities have a central role in achieving synergies toward their mutual reinforcement. The CRPD review yields in-depth recommendations and provides a platform for cooperation between OPDs and the government, primarily the disability focal point. The HLPF provides another type of exposure for civil society before high-level political actors. While time and space are more restricted at the HLPF, meaning that OPDs need to vie for attention, the return in political capital can be significant. Over the years, OPDs have visibly gained ground at the HLPF. Thanks to the support and guidance of the Stakeholder Group of Persons with Disabilities, OPDs are participating at national, regional, and global SDG fora, and, as a result of this increased engagement, there are growing references to persons with disabilities in VNR processes as well as explicit mention of implementation of the CRPD by States in their VNR presentations (Lockwood, n.d.). On its side, since 2016, the Committee, encouraged by OPDs, has been making explicit references to the SDG goals and targets in its recommendations, thereby connecting the legal obligations under the Convention with the political commitments under the 2030 Agenda.

On the face of it, the adoption of the SDGs and its attention to persons with disabilities bring about a propitious climate to advance their rights and create more

Table 1 Comparison of CRPD and SDG monitoring and reporting processes

	CRPD	2030 Agenda and the SDGs
Adoption	Unanimous adoption at the General Assembly, 2006 185 states parties including the European Union	Unanimous adoption at the General Assembly, 2015
Nature of instrument	International treaty with legally binding provisions	Global political commitment
Call for data collection at the national level and beyond	Article 31 puts forward the obligation for states to engage in data collection and disaggregation to help assess the implementation of the convention and to identify and address the barriers faced by persons with disabilities in exercising their rights	Goal 17, target 18, on capacity-building to support developing countries to produce more high-quality, timely, and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location, and other characteristics relevant in national contexts The goals and targets are followed up and reviewed through the global indicator framework, with data compiled and transmitted from the national, regional, and global levels
Call for monitoring at the national level	Articles 33(2) and 33(3) require the designation of an independent national monitoring mechanism with civil society participation	The 2030 Agenda encourages Member States to conduct regular and inclusive reviews of progress at the national and subnational levels which are country-led and country-driven
Participation by OPDs at the national level	Article 33(3) calls for the involvement and full participation of organizations of persons with disabilities and their representative organizations in the monitoring process and, more broadly, in decision-making processes under article 4(3)	Reviews should draw on contributions from indigenous peoples, civil society, the private sector, and other stakeholders, in line with national circumstances, policies and priorities (Para 79, A/RES/70/1)
International monitoring process		
International monitoring mechanism	Periodic review by the Committee on the rights of persons with disabilities	Voluntary National Review at the high-level political forum
Year of first review	2011	2016
Number of review as of 30 June 2022	105 country reviews held - 99 countries with 6 countries having undergone a second review	247 VNRs held - 176 countries with 58 countries having undergone more than one VNR
Nature of review	Review by independent experts	Peer review by states
Length of formal exchange	6 hour dialogue	30 minute for first time review (divided into 15 minute of presentation by the state and 15 minute of questions and responses)

(continued)

Table 1 (continued)

	CRPD	2030 Agenda and the SDGs
		20 minute for states being reviewed again (divided into 10 minute of presentation by the state and 10 minute of questions and responses)
Scope of review	Comprehensive on the rights of persons with disabilities under articles 1 to 33 of the CRPD	Countries are encouraged to review all 17 SDGs (UNDESA, 2021); however, a specific theme and specific goals are designated for each HLPF (without prejudice to the integrated, indivisible, and interlinked nature of the Sustainable Development Goals). The themes and goals are designated through a General Assembly resolution (United Nations, 2016, 2021)
Participation by OPDs in the review process	Several opportunities for OPDs and civil society to share their views, both ahead of the adoption of the list of issues and before the Committee's dialogue with the state party, including: – Submission of written information – Participation in formal private briefings – Informal meetings with individual Committee members	Opportunity for OPDs to submit information and pose questions, exclusively through the stakeholder Group of Persons with disabilities
Outcome document of the review	Results in the adoption of concluding observations, a document of recommendations (approximately 12 pages long)	Results in brief reports on each state and a general summary covering the whole HLPF
Follow-up mechanism(s)	Follow-up through: – The Committee's short-term follow-up mechanism targeting specific identified recommendations – Next review in the periodic review cycle by the CRPD Committee – Other treaty body reviews	No formal follow-up mechanism or structure Eventually, a topic can be revisited in a future VNR, for example, subsequent reports could address "how challenges in implementation, including persistent challenges, were overcome" (UNDESA, 2021)

inclusive environments and societies. However, such opportunities are conditional on the understanding that there is a shared vision among stakeholders of what it means to include persons with disabilities. In practice, this common vision is often lacking: the CRPD is still a relatively young human rights treaty, and the human rights-based approach to disability continues to be misunderstood and misinterpreted by States and other actors. Further, for a long while, there was an absence of guidance on how to measure progress in upholding the rights of persons with disabilities, as well as a persistent lack of data on persons with disabilities to inform monitoring.

Hence, the risks could be foreseen even before the 2030 Agenda was formally adopted. The greatest threat was that the standards embodied by the CRPD and the Committee's jurisprudence – this *acquis* – could be diluted, forgotten, or replaced by actions on persons with disabilities taken in the name of the SDGs, but that fall short of the CRPD. In effect, any of the above would result in a loss and reversal of the long fought for *acquis*. For example, SDG Target 8.5 calls for achieving full and productive employment and decent work for all, including persons with disabilities. The CRPD Committee has been resolute that persons with disabilities should have opportunities to access work and employment in the open labor market on an equal basis with others with equal protection of their labor rights. Despite this standard, many States continue to "employ" persons with disabilities, particularly persons with intellectual disabilities, in segregated work settings where they are often denied labor rights including a minimum wage. Target 8.5 may drive States to enhance and expand these practices in their efforts to lower the unemployment rate of persons with disabilities (see indicator 8.5.2), thereby undermining the rights-based approach to the employment of persons with disabilities and ultimately threatening their effective inclusion and participation in society.

Bridging the Gap: OHCHR's SDG-CRPD Resource Package

In recognition of these opportunities and threats, OHCHR conceived a project to develop tools to help States and all stakeholders to implement the SDGs guided by the CRPD. With the support of the European Union, the Bridging the Gap I project began in 2016 and concluded in 2020 with the launch of the SDG-CRPD resource package. The resource package aims to promote the rights, participation, and inclusion of persons with disabilities in the implementation of the 2030 Agenda, in line with the CRPD. It includes:

- Human rights indicators for the CRPD.
- Data sources guidance.
- Policy guidelines on realizing the SDGs informed by the CRPD.
- Training materials and videos.

The resource package primarily targets States which are responsible for both SDG and CRPD implementation, but it can serve all stakeholders playing a role in the implementation and monitoring of the SDGs and CRPD including development actors, UN agencies, donors, national human rights institutions, national statistics offices, and civil society including organizations of persons with disabilities. All the resources are designed to be complementary and reinforce disability-inclusive implementation of the SDGs. While an overview of the policy guidelines and other resources are provided, the focus will more specifically be directed at the human rights indicators on the CRPD as a means to converge the implementation and monitoring of the CRPD and the SDGs.

Human Rights Indicators on the CRPD

The human rights indicators on the CRPD function similar to the SDG indicator framework, in that they propose measures that enable tracking progress with respect to specific provisions. In particular, human rights indicators track progress in the realization of rights and can contribute to identifying gaps in the implementation of human rights standards.

The human rights indicators on the CRPD were developed in line with OHCHR's methodology on human rights indicators (UNOHCHR, 2012); they are based on international human rights standards as enshrined in the CRPD and CRPD jurisprudence, as well as other human rights treaties, and are divided into three types of indicators to measure the commitments (structural indicators) and efforts (process indicators) by States to meet their human rights obligations, as well as the results (outcome indicators) in ensuring the enjoyment of human rights. The CRPD indicators comprise universally applicable indicators, both qualitative and quantitative, which can be adapted to specific national and local contexts.

For example, the indicators on Article 24 of the CRPD on inclusive education put forth a structural indicator looking at the State's commitment: specifically whether legislation has been enacted that ensures inclusive education for all students (indicator 24.1). Process indicators seek to evaluate the efforts made to achieve inclusive education, for example, the proportion of schools with accessible infrastructure and materials for students with disabilities (indicator 24.11(d)) or the budget allocated to ensure inclusive education in mainstream settings compared to budget allocated to segregated settings (indicator 24.24). And outcome indicators seek to assess the level of enjoyment of the right to education: i.e., rates of persons with disabilities relating to enrolment, attendance, promotion, completion, dropping out, and out of school across all levels of education, disaggregated by several categories including sex, age, and disability (indicator 24.27) (Table 2).

The human rights indicators on the CRPD are key to facilitating understanding and implementation of the Convention's provisions. They serve to give both substantive and practical guidance of each CRPD provision in terms of reflecting the human rights standard and providing steps to translate the standard into policy and practice. As such, the indicators converge understanding on what the provision entails and how to measure progress in its implementation.

In addition, the CRPD indicators incorporate SDG indicators, showing the link between the two instruments and demonstrating how efforts and actions to uphold the rights of persons with disabilities mutually reinforce both. Many SDG indicators have been included as CRPD outcome indicators to capture the enjoyment of the right by persons with disabilities (see above in table SDG indicator 4.a.1 which doubles as CRPD indicator 24.11). For example, SDG indicator 11.7.2: Proportion of persons victim of physical or sexual harassment, by sex, age, disability status and

Table 2 Example of different types of indicators relating to Article 24 of the CRPD on the right to education

Type of indicator	Purpose	Indicator example
Structural	Assesses commitment of the state in policy and legislation	24.1 Legislation enacted that ensures inclusive education for all students, including students with disabilities in public and private settings across all levels of education
Process	Evaluates the efforts toward translating the commitment into action	24.11 Proportion of schools with access to: (a) electricity; (b) the internet for pedagogical purposes; (c) computers for pedagogical purposes; (d) adapted infrastructure and materials for students with disabilities; (e) basic drinking water; (f) single-sex basic sanitation facilities; and (g) basic handwashing facilities (as per the WASH indicator definitions) (SDG indicator 4.a.1) 24.24 Budget allocated and spent to ensure the right of persons with disabilities to inclusive education in mainstream settings, as compared to as compared to budget allocated and spent on segregated/separated education settings, whether in mainstream or special schools
Outcome	Assesses the level of enjoyment of the right resulting from the commitments and efforts taken	24.27 Rates of persons with disabilities out of school, enrolled, attending, promoted by grade, completing, and dropping out in mainstream primary, secondary, tertiary educational institutions, vocational training, lifelong learning courses, as compared to others, disaggregated by sex, age, disability, minority or indigenous background, grade and level of education

place of occurrence, in the previous 12 months, doubles as CRPD indicator 16.31, one of the outcome indicators under Article 16 of the CRPD which seeks to ascertain the extent to which persons with disabilities are protected from exploitation, violence, and abuse, compared to others.

Where the SDG indicator does not have a particular focus on persons with disabilities, the CRPD indicators have incorporated the SDG indicators and expanded them by adding in the call for disaggregation by disability: e.g., proportion of population in a given age group achieving at least a fixed level of proficiency in functional literacy and numeracy skills, by sex (SDG indicator 4.6.1), *disability and minority or indigenous background* (CRPD indicator 24.29). Enhanced data collection and disaggregation by disability reflect the obligations under Article 31 of the CRPD and the commitment under SDG Target 17.18 (see above, section "The CRPD and SDG Monitoring Frameworks"). Not only does data collection and disaggregation by disability, alongside other characteristics, facilitate assessment and monitoring of the impact of measures on persons with disabilities; it helps to identify patterns of discrimination and exclusion specific to persons with disabilities and among different groups of persons with disabilities. Furthermore, it serves as an evidence base to reshape policy approaches.

While the use of indicators is growing in parallel to the call for a data revolution, it is necessary to be mindful of their limits. Indicators provide a snapshot of how a situation looks at a given moment. On their own, many indicators may not be capable of assessing advancement of implementation and will require ongoing monitoring and collection of data over time to determine and track progress. In any and every case, indicators should not be used in isolation: given the interdependent and indivisible nature of human rights, indicators should be looked at in unison and holistically, not only to gauge advancement but also to better pinpoint the gaps which impede the fulfilment of human rights obligations. In addition, indicators have a specific purpose and are thus limited. They are one kind of tool; given their necessary brevity and focus on measurement, their use and effectiveness are enhanced when complemented by other monitoring tools and methodologies such as case studies, testimonies through interviews and focus groups, and academic and participatory research, among others.

Data Sources Guidance

The absence of data related to persons with disabilities has been a longstanding barrier to shaping laws and policies that improve the development, access, and exercise of their rights on an equal basis with the rest of society. Identifying data sources and their gaps is key to ensuring that government action is informed to better reach out to those who are left behind, including persons with disabilities. The Data Sources Guidance provides a compilation of existing sources of data that can be used to respond to and provide a measure for the outcome indicators of the human rights indicators on the CRPD. For each article, the outcome indicators are listed, accompanied by examples of data sources which can be used to populate the indicator. The guidance categorizes outcome indicators into three categories: 1) indicators for which countries are already producing relevant data; 2) indicators for which the data is being produced but not yet disaggregated by disability or where the data exists but is not yet being reported on; and 3) indicators for which no example of a data source was found. The guidance seeks to provide examples of data collection efforts that can be useful for countries in thinking through the best way to populate these indicators in their own contexts. In doing so, the guidance also sheds light on those areas where further efforts are needed. Given the global call to mobilize data collection and disaggregation, it is expected that new methodologies and data gathering tools will be developed to meet this obligation and progressively address the data deficit concerning persons with disabilities.

Policy Guidelines

The policy guidelines provide guidance goal by goal (or by clusters of goals) on steps that need to be taken by policymakers to ensure that the SDGs are realized for persons with disabilities. The guidelines have been designed to be used both as a cohesive set and as standalone components. The policy guidelines are composed of components specific to SDG 1 (no poverty), SDG 3 (good health and well-being), SDG 4 (quality education), SDG 5 (gender equality), SDG 8 (decent work and economic growth), SDG 11 (sustainable cities and communities), and a "Foundations guideline" considered a precursor to all guidelines. The Foundations guideline covers key concepts of the CRPD and structural requirements to create an enabling legal, policy and programming environnment for disability inclusion, based on SDG 10 (reducing inequalities), SDG 16 (peace, justice, and strong institutions), and SDG 17 (partnerships for the goals). In addition, six thematic briefs provide information and recommended actions in relation to food and nutrition, clean water and sanitation, climate change and disaster risk reduction, rural areas, tourism, and research and innovation, each covering a range of SDG goals and targets. References to related CRPD indicators, data sources, training materials, and videos are provided throughout policy guidelines to reinforce the importance of connecting implementation with data and monitoring as well as implementation, capacity-building, and awareness-raising.

Training Materials and Videos

The training materials and videos are structured to mirror and build on the components of the policy guidelines; each policy guideline is accompanied by a training module and a short video. They serve to build capacity and raise awareness on how to apply the human rights-based approach to disability across these policy sectors including ensuring the participation of persons with disabilities in the design and monitoring of related laws and policies. The training modules can be used independently and together and be tailored to the interests of different participants.

The Added Value of the SDG-CRPD Resource Package

The SDG-CRPD resource package can help drive SDG and CRPD implementation. The human rights indicators on the CRPD, in particular, serve to track progress of SDG implementation as it relates to persons with disabilities. The CRPD indicators provide an avenue for States to assess and report on their progress in implementing the rights of persons with disabilities, not only within the context of the CRPD review but also for reporting within the framework of the VNR at the HLPF and monitoring the progress of SDG implementation in the regional and national contexts. VNR guidelines give instruction on submission of data using the SDG indicators and also encourage countries to refer to complementary and priority indicators identified at regional and national levels, opening up space for making use of the human rights indicators on the CRPD (UNDESA, 2021). For example, realizing Goal 5 on gender equality for women and girls with disabilities as well as other goals and targets inclusive of women and girls with disabilities could be guided by the indicators on Article 6 of the CRPD and other related articles. The CRPD indicators bring complementary information to SDG indicators essential to uncover discriminatory practices which otherwise may go unnoticed and remain unaddressed. For instance, SDG Target 16.7 calls on States to "ensure responsive, inclusive, participatory and representative decision-making at all levels," and accompanying SDG indicators intended to verify this commitment are:

> 16.7.1: Proportions of positions (by sex, age, persons with disabilities, and population groups) in public institutions (national and local legislatures, public service, and judiciary) compared to national distributions
> 16.7.2: Proportion of population who believe decision-making is inclusive and responsive, by sex, age, disability, and population group

While the first indicator captures the diversity of people in decision-making positions including elected posts, and the second indicator captures the perception of inclusiveness and responsiveness in decision-making by different population groups, neither serve to identify a common barrier which excludes persons with disabilities from participating in voting and standing for election. Many country's constitutions and electoral laws continue to deny persons with disabilities from participating in decision-making on the basis of actual or perceived impairment UNDESA (2018), including having been formally restricted of one's legal capacity; being characterized as "of unsound mind," "insane," "incompetent," and "incapable"; on account of physical or "mental" "unfitness"; related to one's ability to write, read, and speak the official language; or due to lack of accessibility of voting procedures or denial of access to voting polls. Neither SDG indicator touches on this widespread violation which must be tackled in order to leave no one behind in accomplishing SDG 16. CRPD indicators on Article 29 of the CRPD (participation in political and public life), in particular indicator 29.2, do clearly draw attention to this and call for checking that there are "no provisions in the constitution, legislation or regulations which restrict the rights of persons with disabilities to vote, be elected and hold office and perform all public functions."

The SDG-CRPD resource package, in particular the CRPD human rights indicators in connection with the policy guidelines, can also help to guide and tailor SDG implementation to be responsive to and inclusive of persons with disabilities. It can benefit law, policy, and other decision-makers across all levels of government to know what kind of steps are needed to transform the legal, policy, and budgetary frameworks to include persons with disabilities. In addition, the package serves as a tool for civil society, including organizations of persons with disabilities, and national human rights institutions to hold the government accountable, as well as for international cooperation agencies, UN agencies, donors, and others to assess a State's progress and setbacks in proposing projects, investment, and other forms of support.

Closing Considerations

The CRPD and the Sustainable Development Goals share a common vision for a world and society which values each and every individual and enables their participation and inclusion. The instruments create important opportunities to advance the rights of persons with disabilities by building momentum and calling for the involvement and collaboration of diverse actors. Monitoring offers a platform for engagement, at the heart of which lies the lived experiences of rights holders captured through documenting and measuring, including through the use of indicators. Indicators enhance implementation through their dual mission of description and prescription.

The use of the human rights indicators on the CRPD, together with the totality of the OHCHR's SDG-CRPD resource package, has immense potential to converge and consolidate efforts of a wide array of stakeholders, as attested by recent application of the indicators. Following a workshop held in Asunción in September 2019 centering on the CRPD indicators, an accountability and indicators framework for Paraguay's National Action Plan for the Rights of Persons with Disabilities 2015–2030 was adopted. The workshop, coordinated by Bridging the Gap II, invited OHCHR to discuss the human rights indicators on the CRPD with the National Secretariat for the Human Rights of Persons with Disabilities and Paraguayan officials from various ministries. The adopted National Action Plan is structured in 17 axes accompanied by 109 guidelines. For each guideline, at least one indicator is identified and categorized as *structural, process, or outcome* and accompanied by a data source. A few references to SDG indicators are also integrated, though this could have been applied more consistently. The approach and substance of the National Action Plan's indicators reflect the influence of the human rights indicators on the CRPD and augur well for mutual reinforcement of the CRPD and SDGs.

Furthermore, the indicators are contributing to research initiatives to enhance rights-based studies which prioritize the perspective and lived experiences of persons with disabilities. For example, a research group at McGill University have developed data mining methodology based on the CRPD indicators. This methodology is being used in a global COVID-19 monitoring project to analyze pandemic responses for persons with disabilities across 16 countries. These results will be key to understanding the effectiveness of actions as well as to identify the gaps to improve policy responses. They will also serve as important data and evidence for reporting by States and civil society to the treaty bodies as well as in the context of the VNRs, for example, this year's HLPF will be dedicated to building back better from the COVID-19 pandemic while advancing the 2030 Agenda for Sustainable Development.

These are just a few pioneer efforts that have put the CRPD at the center of national and global policy implementation and monitoring. The success and legacy of the SDGs are necessarily bound to the CRPD, and the SDG-CRPD resources, particularly the CRPD indicators, help to pave the way to a disability-inclusive 2030 and beyond.

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Disability Rights Monitoring: Focus on the Sustainable Development Goals

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Elizabeth M. Lockwood

Contents

Abstract

The ambitious 2030 Agenda for Sustainable Development and its Sustainable Development Goals (SDGs) created the space for persons with disabilities and their representative organizations to be at the center of global sustainable development processes. In turn, organizations of persons with disabilities (OPDs) have meaningfully engaged in advocacy to ensure the rights of persons with disabilities are realized in national policies. Yet, despite incredible efforts, persons with disabilities remain left behind after 5 years into the implementation of the SDGs, particularly due to the lack of disability data to monitor the SDGs. This entry explores the evolution of advocacy of the inclusion of persons with disabilities into the 2030 Agenda, participation in follow up and review mechanisms, and how this in turn influences national policies.

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Introduction

The adoption of the 2030 Agenda for Sustainable Development (2030 Agenda) and its Sustainable Development Goals (SDGs) in 2015 marked a new phase of ambition for global sustainable development. The Agenda is the culmination of more than 2 years of intensive public consultation and engagement with civil society and other stakeholders, including organizations of persons with disabilities from around the world to build upon the achievements of the Millennium Development Goals (MDGs) and to address their unfinished business, particularly in reaching the most marginalized groups.

Since the adoption of the 2030 Agenda, persons with disabilities and their representative organizations have been increasingly advocating to eradicate poverty, reduce inequalities, and gather disability data through the realization of the Sustainable Development Goals (SDGs). With the SDGs, there are new opportunities for engagement for civil society and other stakeholders, including organizations of persons with disabilities and allies. It is imperative that the legally-binding UN Convention on the Rights of Persons with Disabilities (CRPD) and political commitment of the SDGs are interlinked to achieve the inclusion of persons with disabilities in society. Organizations of persons with disabilities have been engaged in the monitoring and review of the CRPD, as well as in the follow-up and review of SDG implementation. This provides organizations of persons with disabilities with increased representation and momentum at the global and regional levels of sustainable development, which in turn strengthens national advocacy for disability rights.

An Inclusive Global Agenda for Sustainable Development

The Millennium Development Goals (MDGs), eight goals agreed in 2000, to end extreme poverty by 2015 had a tremendous effect on the collaboration and prioritization of international development during their 15-year span. Yet, persons with disabilities were not referenced in the MDGs and as a result were excluded from many important development initiatives and funding streams around the world despite making up an estimated 15% of the world's population and being overrepresented among the most impoverished in the world (World Health Organization & The World Bank, 2011; Banks & Polack, 2015). In fact, the 2030 Agenda highlights that more than 80% of persons with disabilities lives in poverty. Such exclusion invigorated the global disability rights movement to work tirelessly to combat such discrimination.

One subsequent transformative achievement for persons with disabilities was the adoption of the CRPD in 2006 that (as of May 2022) 185 nations and regional integration organizations have ratified. The adoption of the CRPD represented a fundamental shift in how persons with disabilities were regarded, moving away from a medical view of disability towards a human rights approach. Uniquely providing both a human rights and development framework, the CRPD redefined what it means to build truly inclusive and sustainable societies, providing the groundwork for future advocacy.

Building on this momentum through tireless and coordinated advocacy from organizations of persons with disabilities and partners, the 2030 Agenda for Sustainable Development resulted in meaningful inclusion of persons with disabilities. On September 25, 2015, the United Nations General Assembly officially and unanimously adopted Resolution A/RES/70/1 "Transforming our world: the 2030 Agenda for Sustainable Development" (2015). The 2030 Agenda represents the first global agenda of its kind in scale and ambition and encompasses social development, climate change, and economic development. The Agenda is a substantive 35-page document containing five sections one of which comprises the SDGs. All sections of the Agenda are important, yet the main focus, particularly regarding implementation, centers on the 17 SDGs and its related 169 targets. The SDGs and targets focus on a broad range of sustainable development issues.

Persons with disabilities are explicitly referenced 11 times throughout the Agenda. These are found in paragraphs on human rights (paragraph 19), vulnerable groups (paragraph 23), education (paragraph 25), and data disaggregation (paragraph 74, g). Additionally, there are seven references in the SDGs on education (Goal 4), employment (Goal 8), reducing inequalities (Goal 10), sustainable and inclusive cities (Goal 11), and data (Goal 17). There are also numerous inexplicit references to persons with disabilities, such as being included in "vulnerable groups" (defined in paragraph 23) and is referenced 18 times throughout the Agenda. Additionally, the commitment to leave no one behind is a foundational element of the Agenda and the SDGs are inherently interlinked, inclusive, and for all people.

In terms of monitoring the SDGs, the 2030 Agenda calls for a global indicator framework indicating that the Goals and targets will be followed up and reviewed using a set of global indicators, complemented by regional and national-level indicators developed by member states (UN General Assembly, 2015: para 75). The Inter-agency and Expert Group on SDG Indicators (IAEG-SDGs) was established by the UN Statistical Commission at its 46th session in March 2015 to develop the indicator framework for the monitoring of the Goals and targets of the 2030 Agenda at the global level and to support its implementation. The global indicator framework was agreed upon, including refinements of several indicators, at the 48th session of the UN Statistical Commission in March 2017, and was subsequently adopted by the United Nations General Assembly on July 6, 2017 (UN General Assembly, Resolution A/RES71/313, 2017). The global indicator framework also contains 11 indicators explicitly referencing persons with disabilities in the areas of poverty eradication, education, employment, reducing inequalities, sustainable and inclusive cities, and peaceful and inclusive societies. Also included in the framework is the chapeau on disaggregation that states "Sustainable Development Goal indicators should be disaggregated, where relevant, by income, sex, age, race, ethnicity, migratory status, disability and geographic location, or other characteristics, in accordance with the Fundamental Principles of Official Statistics" (A/Res/71/313).

The inclusive 2030 Agenda provides significant space for the participation, leadership, and recognition of persons with disabilities and their representative organizations as active contributing members of society. Moreover, with the commitment to leave no one behind as a foundational element of the 2030 Agenda, the rights of persons with disabilities for the first time are included as a central issue in sustainable development. With explicit references, the 2030 Agenda, like the CRPD, has provided equal opportunities for the participation of persons with disabilities and their representative organizations to meaningfully address the institutional, physical, communication, legal, and attitudinal barriers that have inhibited their full participation within human rights and development dialogues.

It is essential that the implementation of the SDGs is in line with and build upon existing international and national commitments and mechanisms, including the CRPD as this will ensure that exclusion and inequality are not created or perpetuated for persons with disabilities. The SDGs apply to all countries and draw particular attention and commitment to include persons with disabilities in all aspects of sustainable development under a number of goals and targets that are also found in the CRPD. In addition, several CRPD Articles are cross-cutting and should be included in the implementation of the SDGs. Some examples include equality and non-discrimination (Article 5), women with disabilities (Article 6), children with disabilities (Article 7), accessibility (Article 9), access to justice (Article 13), statistics and data collection (Article 31), international cooperation (Article 32), and national implementation and monitoring (Article 33).

Persons with disabilities must continue to be included in sustainable development processes as pervasive discrimination against persons with disabilities has an economic cost to all of society. And thus, if persons with disabilities are not agents of change and included in the implementation of the SDGs, then the Agenda will not be achieved for all.

Monitoring the SDGs to Ensure the Inclusion of Persons with Disabilities

The monitoring mechanism for the SDGs, called follow-up and review under the 2030 Agenda, is voluntary and country-led. Although the 2030 Agenda is not legally binding, there is political pressure to implement the SDGs. This pressure is especially evident at the High-level Political Forum (HLPF), which is the main global platform for the follow-up and review of the SDGs where countries volunteer to report on their national implementation of the SDGs with voluntary national reviews (VNRs). In addition, regional reviews, led by UN regional commissions, focus on regional learning and feed into the HLPF.

The VNRs are a central feature of the HLPF and are regularly undertaken by countries in the Global North and South. The VNRs provide a platform for partnerships, including through the participation of major groups and other stakeholders in which persons with disabilities are represented via the Stakeholder Group of Persons with Disabilities. Each year, countries that volunteer to present a VNR at the HLPF hold national-level consultations to prepare their VNR. These reports demonstrate a country's progress in achieving the SDGs and also identifying gaps in national policies. Voluntary national reviews also provide opportunities for civil society stakeholders, including OPDs, to engage with their governments and present opportunities to ensure stronger civil society coordination at the national level, advocate for united implementation, break down silos and open doors, participate in new institutional arrangements, secure funding, bring attention to civil society messages at the global level, engage in national dialogues, and hold governments accountable (Together 2030 et al., 2018).

The VNRs are presented at the global level at the HLPF, but build on a monitoring process at the national and regional levels. Voluntary national reviews are voluntary and country led, and thus there is no formal structure or follow-up mechanism for these reports. There are voluntary common reporting guidelines for member states that were initially prepared by the UN Secretary-General in 2015 and have been updated adapting to lessons learned. These only serve as a guide and are not formal guidelines (UN General Assembly, 2016, 2019). Many OPDs have followed their government's SDG implementation plans and have engaged in the review process to push for the inclusion of persons with disabilities and to address the gaps that persons with disabilities face.

The Importance of Disability Data to Measure the SDGs

Data provide essential information on the status of the implementation of the rights of persons with disabilities. Moreover, data can identify existing policy gaps and barriers faced by persons with disabilities to support policymakers to amend existing policies, regulations, and programs.

Countries are mandated to collect data on persons with disabilities. Specifically, CRPD Article 31 calls for States Parties to collect appropriate information, including statistical and research data, to enable them to formulate and implement the Convention. Moreover, the 2030 Agenda calls for significant increase of "the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts" (target 17.18). In addition, follow-up and review processes at all levels "will be rigorous and based on evidence, informed by country-led evaluations and data which is high-quality, accessible, timely, reliable and disaggregated by income, sex, age, race, ethnicity, migration status, disability and geographic location and other characteristics relevant in national contexts" (UN General Assembly, 2015: para 74, g). Additionally, the global indicator framework has 11 disability-inclusive indicators.

Despite these global mandates, disability data overall are *not* being collected by national statistical offices for SDG monitoring. In some cases, a lack of resources thwarts household-level surveys to include adequate levels of disaggregation. While there are many efforts to improve the disaggregation of data, challenges remain such as a notable lack of disaggregated data on persons with disabilities (IATF, 2017, p. 118). Currently, the lack of data, particularly for marginalized groups, is a considerable impediment in fulfilling the SDGs.

There is not a firm process yet on how to address the gap of gathering disability data, but statistical offices are engaging more on marginalized groups and their experiences. In many cases, there is a mechanism to gather disability data at the national level, but getting this information from the global level is much more challenging. As a consequence, there is a lack of information on the experiences of persons with disabilities creating a major barrier for inclusion and exacerbating inequalities (IAEG-SDGs, 2020).

There has been recent progress at the global level with custodian (UN) agencies finding solutions to start collecting disability data to measure the SDGs. There is a greater focus on unofficial data to measure the SDGs, including citizen-driven data to address data gaps, especially for marginalized groups. There is an increased focus on data disaggregation and to reach the furthest behind. The regional focus is becoming more evident and we should support partners to engage regionally in these processes. The topic of disability data is increasingly included in the IAEG-SDGs meetings, which is a tremendous improvement from the start of the meetings in 2015 (IAEG-SDGs, 2020; Stakeholder Group of Persons with Disabilities et al., 2020).

Ensuring that the rights of persons with disabilities are included in all development efforts requires the routine collection of evidence-based data across all sectors as a means to monitor and ensure that persons with disabilities are fully participating in society. Below are some key recommendations from the Stakeholder Group of Persons with Disabilities (2020b) for governments to address data and monitoring gaps:

- Official statistical bodies should collect and disaggregate data by disability using the Washington Group short set of questions and the Washington Group and UNICEF Child Functioning Module. These modules are internationally comparable, efficient, and easy to incorporate into ongoing data collection of national statistical systems, making them sustainable and suitable for disaggregating by disability status and monitoring progress in attaining the Sustainable Development Goals on an ongoing basis. It is important to note that other tools are appropriate when a more detailed understanding of sectors or barriers and enablers to inclusion is required. Also, to adequately capture information on psychosocial disabilities, more complex questions are needed than what are included in the short set.
- Use community-driven data to complement official statistics to contribute to SDG implementation inclusive of persons with disabilities.

- Invest in data for disability-inclusive development and to build capacity in stakeholders, especially organizations of persons with disabilities, to be better prepared to survey their communities.
- Consult and meaningfully include persons with disabilities and their representative organizations on the design, implementation, and monitoring of SDG plans in line with the CRPD.
- Allocate budget for the inclusion of persons with disabilities and to measure inclusion to leave no one behind.
- Ensure that statisticians, policymakers, OPDs, and allies have dialogue and exchange to learn from each other and use available data to address challenges and gaps in policies.

The 2030 Agenda and OPD Advocacy

Organizations of persons with disabilities have an important role to play nationally, regionally, and globally on advocating for disability rights whether to assess how the CRPD is being implemented or how the implementation of the SDGs is including persons with disabilities. The 2030 Agenda provides the space for the disability movement to engage in the sustainable development dialogue, which is explored next.

Advocacy Efforts Prior to the Adoption of the 2030 Agenda

Organizations of persons with disabilities and partners, such as the International Disability Alliance (IDA)[1] and the International Disability and Development Consortium (IDDC)[2] were instrumental in engaging in joint advocacy during the negotiations leading to the adoption of the 2030 Agenda. It is important to highlight that this chapter focuses on the collaborative advocacy efforts carried out by IDA and IDDC with recognition that other initiatives and organizations also contributed to efforts to promote the inclusion of persons with disabilities in the process leading to the adoption of the 2030 Agenda and subsequent implementation.

Joint advocacy efforts by IDA and IDDC were carried out with member states to influence negotiations in the open working group on sustainable development goals and post-2015 intergovernmental negotiations. The open working group on sustainable development goals was composed of 30 member states and held meetings from early 2013 to July 2014 followed by the post-2015 intergovernmental negotiations with all member states from January 19 to August 2, 2015.

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[1] More information on the International Disability Alliance: https://www.internationaldisabilityalliance.org

[2] More information on the International Disability and Development Consortium: https://www.iddcconsortium.net

Since persons with disabilities were excluded from the MDGs, there was ample evidence of how and why this exclusion occurred and how this could not happen again in the new global agenda. Strategically, the World Health Organization and the World Bank world report on disability (2011) provided the important evidence that the world is comprised of one billion persons with disabilities of whom 80% resides in the Global South, and consequently are disproportionately left behind in sustainable development. This report was an incredibly important tool in advocating for the inclusion of persons with disabilities in the new global agenda since it provided evidence on the situation of persons with disabilities worldwide.

In March 2014, IDA, in partnership with IDDC, hosted a conference in Nairobi, Kenya, to deepen the dialogue on the African continent between national, regional, and global OPDs. More than 100 participants from 17 African countries; regional representatives from Latin America, Europe, Australia, and Asia attended the meeting. At the end of the conference, the participants among high-level governmental representatives and United Nations agencies, adopted the event's outcome document, the Nairobi Declaration (International Disability Alliance, 2014). The Declaration highlighted the priorities of persons with disabilities on the African continent within the context of the post-2015 development agenda.

The conference played an important role to influence the open working group on sustainable development goals, and also to provide support to African OPDs to activate some African governments to engage in the post-2015 agenda process. Afterward, there was a significant increase of support from African countries on the inclusion of persons with disabilities in the open working group at the UN in New York, perhaps stemming from the conference and the Nairobi Declaration (Cuk, 2019).

When the report of the open working group on sustainable development goals was released in July 2014, it contained 9 references to persons with disabilities. The International Disability Alliance and IDDC activities greatly contributed to the outcome of this report. During the open working group negotiations, IDA and IDDC delivered 15 statements, organized five strategic events, and prepared five written contributions to consultation processes. IDA organized two high-level side events and carried out 70 bilateral meetings with governments (Cuk, 2019). During this period and following, IDA and IDDC were in regular contact with approximately 80 member states. This outcome symbolized that the joint advocacy strategies were an effective way to create inclusion (Bartha & Lockwood, n.d.).

In time and with experience, advocates learned to ensure a balance between effective and focused advocacy and not overburdening member states with too many requests. In the process, the disability constituency had become one of the stronger stakeholder groups in terms of advocacy and visibility. This both created competition between some stakeholder groups, but also increased collaboration with others, such as Indigenous peoples, older persons, volunteers, and other groups (Bartha & Lockwood, n.d.).

The open working group on sustainable development goals concluded its work with the adoption by acclamation of a set of sustainable development goals in its final session on Saturday, July 19, 2014 after 26 h of uninterrupted negotiations.

Ultimately, member states supported a report (not legally binding) containing 17 goals and 169 targets. This document served as the basis of intergovernmental negotiations that took place from early 2015 until August 2, 2015 concluding with a draft outcome document of the post-2015 development agenda agreed by consensus by member states. This document, with only a few changes, was the final document officially adopted by the UN General Assembly a little over a month later on September 25, 2015 and now known as the 2030 Agenda for Sustainable Development.

Throughout the aforementioned negotiations, discussions of an indicator framework emerged and advocates from IDA and IDDC engaged closely to ensure persons with disabilities were included in what would become the global indicator framework. In addition, the constituency advocated for civil society to have an active, rather than an observer status with the group that would become the IAEG-SDGs. Initially, disability advocates were not actively included in the development of the SDG indicator framework, and in fact were excluded along with other stakeholders, including older persons and volunteers. Advocates continued to push for inclusion and an active role in the subsequent IAEG-SDGs meetings. The aforementioned outcomes are excellent examples of long-term advocacy and effective multi-stakeholder collaboration to create inclusion, meaningful participation, and representation.

Advocacy Efforts in SDG Implementation

Importantly, the 2030 Agenda also amplifies CRPD implementation since the SDGs and their implementation are interconnected and relevant for many Ministries, rather than focusing on only one part of the government. This allows the space for OPDs to approach different Ministries to discuss SDG implementation and at the same time advocate for CRPD implementation, which strengthens the advocacy messages. For example, the implementation of SDG 8 can be linked to CRPD Article 27 to provide information on how to implement this SDG and in addition to strengthen advocacy efforts and inclusion.

At the national level, governments are encouraged to conduct consultations with civil society and other groups, including organizations of persons with disabilities to contribute views on SDG implementation to prepare the voluntary national review that will be submitted later to the HLPF. Inputs into these consultations should feed into the VNR, but this is not guaranteed, as evident in some country reports (International Disability Alliance and Stakeholder Group of Persons with Disabilities, 2017).

After the adoption of the 2030 Agenda, the dissemination of information and trainings from the global level to national OPDs increased awareness about the SDGs and assisted OPDs to more effectively get involved in the VNR process. This information sharing also encouraged the formation of regional constituencies of persons with disabilities to get active in regional SDG processes, such as the Asia Pacific Disability Constituency. Furthermore, organizations of persons with disabilities have used regional forums for networking and advocacy, sharing national-level experiences, and conducting bilateral meetings with governments. Often OPDs at the regional level have contributed to the regional SDG and disability plans and raise awareness on issues related to persons with disabilities to governments, UN agencies, and other civil society groups. This, in turn, has influenced positive change at the national level. Organizations of persons with disabilities have been involved in national consultations, and increasingly so since 2016, through various forms of engagement, which are explored below.

One way to engage in national consultations has been via national OPD umbrella organizations with a collaborative SDG strategy and recommendations for the inclusion of persons with disabilities. The most significant barriers to participation in these consultations have been the lack of accommodations provided by the government for OPDs to attend these consultations, as well as not being invited to the consultations and/or not receiving relevant information (International Disability Alliance and Stakeholder Group of Persons with Disabilities, 2017).

In some countries, disability and development NGOs working on disability rights and disability-inclusive development have been included in OPD advocacy efforts to strengthen advocacy initiatives, create synergy, provide resources and support, and to avoid duplication of efforts, such as the case in Togo, which is an interesting case since it volunteered to report on SDG implementation 3 years in a row (2016, 2017, and 2018). The CBM office in Togo worked in partnership to support the umbrella DPO in Togo, Fédération Togolaise des Associations de Personnes Handicapées (FETAPH), to participate in the VNR consultation process. For example, in 2016, the CBM office in Togo organized a meeting with FETAPH's program department to raise awareness regarding the SDGs. This meeting and further exchanges contributed to the enhanced participation of OPDs in the national SDG implementation process. In 2017, CBM and FETAPH collaborated to complete a form distributed by the Ministry in charge of the National Development Plan to stakeholders, financial partners, and other civil society members. This helped in part increase FETAPH's participation during the second VNR consultation process, which was linked to the National Development Plan, 2018–2022. As an outcome of advocacy efforts at the national level, the government of Togo referenced persons with disabilities three times in the 2017 VNR (Lockwood, 2018).

The UN is also an important avenue for OPDs to engage in national consultations. The UN, including UN agencies at the country level, are mandated to support SDG implementation, and in some situations, the UN has served as a bridge to connect civil society to government on SDG implementation. It has also been strategic for OPDs to build or join national coalitions with other civil society organizations and other stakeholders creating powerful coalitions with unified messages and providing strategic opportunities to engage, learn, and exchange information, such as in Bangladesh, and Kenya.

In Bangladesh, in order to get persons with disabilities engaged into the SDG implementation process, a collective platform called "Disability Alliance on SDGs" was formed on March 9, 2017. The Disability Alliance on SDGs is an alliance comprised of national and international OPDs and NGOs working in the field of disability and development in Bangladesh, and that are also aligning programs with at least one of the 17 SDGs. In May 2017, the Disability Alliance on SDGs released a report on different SDGs under review through the lens of persons with disabilities. It was prepared after several consultations with organizations of persons with disabilities across different parts of the country. This report was shared with the government to influence the country's 2017 VNR, which includes almost 30 references to persons with disabilities and, more recently, in Bangladesh's 2020 VNR, there are 80 references to persons with disabilities. Spotlight reports on the SDGs, such as these, highlight the gaps on the inclusion of persons with disabilities in relevant processes, policies, and programs. While these reports are not officially accepted at the global level at the HLPF, they can be strategic for OPDs to bring attention to issues at national, regional, and global levels and provide a good record for OPDs and governments to monitor progress over time. The Disability Alliance on SDGs continues to be active and is in discussions to conduct in-depth study on COVID-19, the SDGs, and persons with disabilities (CBM Bangladesh, 2020; Government of the People's Republic of Bangladesh, 2017, 2020; The Disability Alliance on SDGs, 2017).

In Kenya, OPDs have been involved in the SDGs Kenya Forum that brings together over 350 civil society organizations working across the 17 Sustainable Development Goals to influence multi-stakeholder policies and actions for the achievement of the SDGs in Kenya. The Forum is a voluntary membership entity open to civil society organizations, government entities, academia, media, and the private sector who focus on the 2030 Agenda, particularly, the Sustainable Development Goals. Since 2017, civil society organizations Society have been submitting progress reports to inform Kenya's Voluntary National Review (VNR). The umbrella organization of organizations of persons with disabilities in Kenya, United Disabled Persons of Kenya (UDPK), is an active member in the Forum.

OPDs have also engaged with their government following the HLPF to assess outcomes and build partnerships at the national level. Not all countries have HLPF follow-up mechanisms established, but OPDs importantly have reminded political leaders that the VNR is not a one-time obligation, but rather an ongoing permanent dialogue. An example of this is from Tajikistan. In 2017, Tajikistan presented its VNR at the HLPF. An OPD representative from Tajikistan with support from the UN, attended and presented at the HLPF. While at the HLPF, the representative learned firsthand the meaning and relevance of the SDGs. As a follow-up outcome after the HLPF, the national OPD organization signed a memorandum of understanding on the SDGs with the relevant Ministry. This action, subsequently accelerated and amplified Tajikistan's ratification of the CRPD in 2018 (Stakeholder Group of Persons with Disabilities, n.d.).

Disability Data Advocacy in the SDGs

The role of OPDs and civil society organizations in filling data gaps is increasingly important since official disability data largely are not being gathered to measure the SDGs with limited available internationally comparable data (IAEG-SDGs, 2020).

Organizations of persons with disabilities are participating in and monitoring the use of data reported at national, regional, and global levels and are advocating for the improved use of data nationally based on the commitments of the SDGs. Organizations of persons with disabilities have an important role to play in highlighting persons with disabilities as a group that has been left behind. Some ways this has taken place are outlined below.

One way has been participating in national-level consultations and providing an analysis with suggestions to address of data gaps in achieving the SDGs. Second, OPDs have worked with national statistics offices to advocate for national improvements to disability disaggregated data and better use of the SDG indicator framework in national reporting on the SDGs. Third, OPDs have engaged in regional forums and the global HLPF to push for improvements to disability disaggregated data and gaps in achieving the SDGs. Fourth, OPDs and advocates have presented and shared key information at global events such as the meetings of the Inter-agency and Expert Group on SDG Indicators, UN World Data Forums, and the UN Statistical Commission sessions largely via the Stakeholder Group of Persons with Disabilities. Fifth, OPDs collaborate with the Washington Group on Disability Statistics, international non-governmental organizations, and the UN system to ensure disability data disaggregation is implemented across policies and programs. And, sixth, in 2019, OPDs and allies via the Stakeholder Group of Persons with Disabilities established a global platform for information exchange, learning and dialogue, sharing of good practices, and collaboration on disability data collection, disaggregation, and analysis called the disability data advocacy working group. From this emerged the first comprehensive disability data advocacy toolkit for OPDs that was launched in November 2020 (Stakeholder Group of Persons with Disabilities et al., 2020).

An example of collective advocacy efforts over time that led to increased participation was how IDA and IDDC pushed for inclusion and an active role in the IAEG-SDGs meetings that were only partially open to civil society and UN agencies. Real change finally took place at the sixth meeting of the IAEG-SDGs in Bahrain in November, 2017. At this meeting, the IAEG-SDGs co-chairs, in response to stakeholder recommendations, agreed to adjust the meeting format for the seventh meeting to allow civil society to have active participation and make presentations along with national statistic offices. This was indeed implemented at the seventh IAEG-SDGs meeting in Austria in April, 2018, and has remained in place as of today. It is important to note that this change also benefited UN Agencies that had also been excluded from the previous closed IAEG-SDGs meetings. Furthermore, at the eighth meeting of the IAEG-SDGs in Sweden in November, 2018, OPDs via the Stakeholder Group of Persons with Disabilities were included as official panelists for the first time, and have continued to regularly be official panelists in the IAEG-SDG meetings since (e.g., in Lebanon and Ethiopia in 2019) and have built a collaborative relationship with the United Nations Statistics Division since, and which continues to this day (Stakeholder Group of Persons with Disabilities et al., 2020).

Influencing National Disability Policies

It is the responsibility of governments to implement the CRPD to fully realize economic, social, and cultural rights of persons with disabilities, yet this does not always come to fruition. CRPD implementation linked with the 2030 Agenda's commitment to leave no one behind in global sustainable development can help move disability rights forward in countries. In fact, the SDGs and the political will behind them can provide new opportunities for OPDs to advocate for the implementation of the legally-binding CRPD in their countries, and using the CRPD and SDG frameworks jointly can help drive advocacy messages. This can strengthen the commitment to the inclusion of persons with disabilities from government officials. Some ways to do this are by building partnerships, using data to inform evidence-based policymaking, supporting development finance, and ensuring accessibility.

Building partnerships and coalitions, especially multi-stakeholder (comprising of non-governmental and governmental actors) partnerships, can provide key opportunities to ensure the rights and inclusion of persons with disabilities into social, economic, and political aspects of society through various forms. Multi-stakeholder partnerships encourage the spirit of the 2030 Agenda by fostering open, transparent, effective, participatory, and inclusive processes and dialogue that promote accountability to citizens, support effective international cooperation, and truly leave no one behind to achieve the 2030 Agenda. Multi-stakeholder partnerships in support of SDG implementation can track progress of implementation to exchange best practices and provide mutual learning.

Stakeholders can learn about various initiatives, implementation methodologies, coordination mechanisms, governance structures, resources, and other valuable information. This includes disability-targeted partnerships with other stakeholders in which persons with disabilities and their representative organizations are key actors in cross–sector dialogues, multi-level platforms, and capacity-building.

Carrying out disability data collection, disaggregation, research and analysis at the national and global levels are instrumental in identifying the gaps and challenges of persons with disabilities and informing evidence-based policies. As recommended earlier and noting some limitations, data disaggregated by disability should be collected using the Washington Group short set of questions and the Washington Group and UNICEF Child Functioning Module while also consulting persons with disabilities and their representative organizations on the design, implementation, and monitoring of SDG plans in line with CRPD Article 33. In addition to disability, data should also be disaggregated by other social categories such as age, gender, ethnicity, migratory status, class/caste, Indigeneity, and other characteristics. Statisticians, policymakers, OPDs, and allies need to learn from each other and use available data to address challenges and gaps in policies.

In terms of development finance, there needs to be better mobilization and use of public resources for the inclusion of persons with disabilities keeping in line with the CRPD. Moreover, governments must allocate budget for the inclusion of persons with disabilities and to measure inclusion to leave no one behind. Cote and Meeks

(2017) found that in most low and middle-income countries in which few significant inclusive policies or programs exist, significant additional public spending is required so persons with disabilities are not left behind. Thus, there is a need for a significant increase of domestic resource mobilization and public spending for the inclusion of persons with disabilities, and at the same, no public expenditures should create or perpetuate barriers for persons with disabilities.

The following section includes two examples of how advocacy led by and/or in partnership with OPDs has influenced national policies in making them more inclusive of persons with disabilities.

The Participation of Organizations of Persons with Disabilities at the HLPF

The 2030 Agenda has increased participation of persons with disabilities in global sustainable development processes. Since the first HLPF after the adoption of the 2030 Agenda in 2016, OPDs have actively advocated for the inclusion of persons with disabilities in national VNR consultations, regional gatherings, and at the global HLPF. This advocacy and participation have strengthened over the years through coordination, coalitions, and exchange of information and learning between the global, regional, and national levels. For example, in 2016, 22 persons with disabilities and advocates attended the HLPF as representatives of the Stakeholder Group of Persons with Disabilities, in 2018, 31 OPDs and advocates attended, and, in contrast, in 2019 (2020 HLPF was in a virtual format so not comparable), 72 persons with disabilities and advocates attended the HLPF. Additionally, in 2018, there were 675 disability references included the 46 VNR written reports and in 2019, there was an increase of 1959 disability references in the 47 VNR reports. This increased inclusion indicates an outcome in part from increased advocacy and participation at all levels (International Disability Alliance, 2016; Stakeholder Group of Persons with Disabilities, 2016, 2017, 2018).

In the 2020 HLPF, persons with disabilities were also meaningfully included despite the online nature of the forum. Persons with disabilities were referenced in key opening sessions throughout the 2 weeks highlighting that disability was a priority area, particularly since the HLPF was linked to the COVID-19 pandemic. More than 30 countries highlighted persons with disabilities in various events, statements and in VNR presentations, such as consulting with persons with disabilities in the VNR process and examples of inclusion of persons with disabilities at the country level, including the implementation of the UN Convention on the Rights of Persons with Disabilities. For example, Comoros, the Kyrgyz Republic, and the Republic of Moldova all highlighted the implementation of the CRPD in their VNR presentations at the 2020 HLPF (UN High-level Political Forum, 2020).

There were excellent examples of meaningful participation and inclusion of persons with disabilities in some VNR presentations, which has begun to increase via advocacy and awareness raising since 2016. For example, The Gambia included a video of The Gambia Federation of the Disabled (The Gambia, 2020) and Seychelles included a video of a young man with a disability from a family with three persons with disabilities who explained how the social protection system has provided accessibility measures, such as ramps in their home creating a more inclusive life (Seychelles, 2020). Additionally, there were stellar examples of accessibility in VNR presentations. Panama included its own captions and a sign language interpreter in its pre-recorded video (Panama, 2020); Slovenia included captions in its pre-recorded video presentation (Slovenia, 2020); and Uganda (2020) included a sign language interpreter in its VNR presentation (Lockwood, 2020; Stakeholder Group of Persons with Disabilities, 2020a).

This is a significant achievement, and with this there is an increased understanding and willingness of persons with disabilities and their representative organizations to engage in the 2030 Agenda implementation, monitoring, and follow-up processes. This growing recognition stems from collective action led by the disability movement, including leaders and members of organizations of persons with disabilities in partnership with disability rights advocates and other partners.

The Leave No One Behind Partnership

The Leave No One Behind partnership hosted by the International Civil Society Centre was launched in late 2017 as a partnership of 12 international civil society organizations. In 2018, the partnership set up national coalitions in five pilot countries in Bangladesh, India, Kenya, Nepal, and Vietnam bringing together national NGOs and civic platforms, as well as community-based organizations.

The partnership's main goal is to make SDG implementation more inclusive and accountable toward those who are furthest behind in society particularly marginalized groups, including persons with disabilities, older persons, youth, women and girls, ethnic minorities, transgender people, street dwellers, and other marginalized groups. The objectives are to have more inclusive SDG implementation that addresses the needs of marginalized groups effectively; use a participatory approach that involves people from communities in data generation and retrieving direct feedback; and carry out dialogue with authorities on policy change, informed through the use of community-driven data and feedback.

Each country identified data gaps and then collected data on the most marginalized groups. Data on the situation of persons with disabilities was collected in each of the five countries, and for example, in India, organizations of persons with disabilities led and collected the set of disability data.

As a result of the communities working with authorities and public service providers at the national and local levels, various policy recommendations emerged on how to make SDG implementation and monitoring more inclusive and accountable. They include: (1) foster collaborative research to close data gaps, (2) strengthen inclusive decision making, (3) improve reporting and accountability; and advocate for budget allocation and government commitments to ensure inclusive SDG implementation and monitoring. These recommendations can be replicated in other countries to ensure inclusive SDG implementation and monitoring.

Conclusion

The adoption of the 2030 Agenda for Sustainable Development and its Sustainable Development Goals has created the space for persons with disabilities and their representative organizations to be at the center of global sustainable development processes. Organizations of persons with disabilities have increasingly engaged in the follow-up and review processes to ensure that persons with disabilities are included in SDG implementation. Since 2015, there has been a marked increase of representation of OPDs in global sustainable development processes, and in turn, in some cases, this has influenced national disability policies and CRPD implementation.

Yet, despite collaborative and persistent advocacy efforts, persons with disabilities remain left behind after 5 years into the implementation of the SDGs, particularly in terms of lack of disability data to monitor the SDGs. This situation has only been exacerbated with the COVID-19 pandemic that is increasing inequalities and creating new and additional barriers for persons with disabilities (Stakeholder Group of Persons with Disabilities, 2020b).

The SDGs cannot be achieved without including those most left behind, including persons with disabilities. Implementation of the CRPD linked with the 2030 Agenda's commitment to leave no one behind in global sustainable development can create a truly inclusive society for all.

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COVID-19 Disability Rights Monitor: State Measures' Impact on Persons with Disabilities During the Coronavirus Pandemic

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Sándor Gurbai and Steven Allen

Contents

Abstract

Allegations are emerging that certain groups of people, including persons with disabilities, are being disproportionately affected by the COVID-19 pandemic and that governments have failed to adopt a disability-inclusive response, resulting in serious human rights violations worldwide. In order to collect

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evidence on the (lack of) state measures concerning the impact of COVID-19 on persons with disabilities, a coalition of seven disability rights organizations launched a major global initiative, the COVID-19 Disability Rights Monitor ("COVID-19 DRM"), soon after the pandemic was declared. Under the framework of COVID-19 DRM, a three-component survey, containing three questionnaires, was created to collect information (i) from governments, (ii) from national human rights monitoring mechanisms, and (iii) from persons with disabilities and their families and representative organizations. The questionnaires were made available in 25 languages on a website established especially for the COVID-19 DRM, and this remained open from 20 April to 7 August 2020, during which period 2,152 online responses were collected from 134 countries around the world. In this chapter, we give an overview of how and why the COVID-19 DRM was created and present the methodology we applied. We show the findings of the survey and share representative testimonies from persons with disabilities and other respondents. We give an overview of the impact of the survey and then we conclude with proposals for consideration of different stakeholders.

Keywords

Disability rights · COVID-19 Disability Rights Monitor · COVID-19 · Coronavirus · Pandemic · Human rights · Independent monitoring

Introduction

In January 2020, news reports and academic papers had started calling attention to a novel coronavirus called SARS-CoV-2 which causes the coronavirus disease (COVID-19). Chaolin Huang et al. reported in the *Lancet* that by 2 January 2020, 41 SARS-CoV-2 infected patients were admitted to hospital in Wuhan, China (Huang et al., 2020). The virus spread rapidly, and on 30 January 2020, Dr. Tedros Adhanom Ghebreyesus, the Director-General of the World Health Organization (WHO), declared that the outbreak constituted a Public Health Emergency of International Concern under the International Health Regulations (World Health Organization, 2020).

The COVID-19 pandemic has created complex and multifaceted issues for people all around the world and has demanded immediate and wise reactions from all sections of society. Governments began taking unprecedented steps including locking downtowns, cities, counties, and even countries. States of emergency have been declared by numerous countries, and serious restrictions have been placed upon the exercise of fundamental human rights in order to try to halt the spread of the virus.

Advocates for persons with disabilities quickly saw that many of the urgent restrictions instituted by states would have a profound impact on persons with disabilities. In May 2020, António Guterres, Secretary-General of the United Nations (UN), highlighted in a policy brief that:

> Even under normal circumstances, persons with disabilities are less likely to access health care, education, employment and to participate in the community. They are more likely to live in poverty, experience higher rates of violence, neglect and abuse, and are among the most marginalized in any crisis-affected community. COVID-19 has further compounded this situation, disproportionately impacting persons with disabilities both directly and indirectly (United Nations, 2020).

Information collection and monitoring of human rights are even more crucial during periods of emergency, assisting policy-makers to effectively target their responses, allocate scarce resources, and prevent disproportionate impacts on segments of the population with enhanced vulnerabilities. In the worrying context of the pandemic, a coalition of seven disability rights organizations joined forces and worked together to develop and launch a major global initiative, the COVID-19 Disability Rights Monitor (COVID-19 DRM), to rapidly collect evidence on the impacts of the pandemic and related state measures on fundamental human rights guarantees.

In this chapter, we present the COVID-19 DRM. We focus on the methodology of the survey that was deployed, and then we show the findings of the survey and share representative testimonies from persons with disabilities and other respondents. We also provide an overview of how the findings from the survey have been used in concrete advocacy initiatives. Finally, we conclude with proposals for consideration of governments, national human rights monitoring mechanisms, as well as to relevant international entities. We address the urgent need for concrete measures to be taken to prevent further violations in the midst of the pandemic, which continues apace at the time of writing, and with a view to preventing widespread human rights violations during future emergencies.

The COVID-19 Disability Rights Monitor

In the first months of 2020, as SARS-CoV-2 started to gain ground globally, national-, regional-, and international-level organizations of persons with disabilities and disability rights organizations began receiving testimonies and complaints about the serious consequences persons with disabilities, their families, and support persons were facing, indicating the emergence of widespread violations of human rights guarantees. These reports related to various aspects, including concerns over the total lockdown of residential institutions, inter alia, for persons with disabilities, the lack of support and reasonable accommodation measures in hospitals and in community settings, a high number of suspended court procedures, a lack of continuity and availability of community-based services, a distinct scarcity of independent human rights monitoring visits to residential institutions for persons with disabilities, multifaceted problems related to the closure of schools and workplaces, etc.

In March 2020, the Validity Foundation reached out to other disability rights organizations and proposed cooperation in order to develop a tool for rapid independent monitoring of state measures concerning the impact of COVID-19 on the rights of persons with disabilities. In part, this call was driven by the lack of coordinated action at an international level and a lack of focus on the part of decision-makers in addressing some of the predictable and immediate consequences of restrictive measures and emergency responses on persons with disabilities. In response to this call to action, seven organizations joined together and formed the COVID-19 DRM Initiative. The seven organizations were as follows: the Validity Foundation-Mental Disability Advocacy Centre, the European Network on Independent Living, Disability Rights International, the Disability Unit at the Centre for Human Rights at the University of Pretoria, the International Disability Alliance, the International Disability and Development Consortium, and the sister organizations Disability Rights Fund and Disability Rights Advocacy Fund. The coalition was international in scope, driven by the objective of gaining an international picture.

A Coordinating Group was established comprised of representatives of the seven organizations, mandated to develop the questionnaires and distributing these as widely as possible. In addition, the Coordinating Group resolved to create a website to promote real-time information-sharing, consciously highlighting the voices of persons with disabilities themselves throughout the survey period. During regular coordination meetings, member organizations met to produce weekly briefs based on data collected and agreed to issue joint statements to call for rapid action concerning emerging themes from the data.

The COVID-19 DRM was endorsed by the then UN Special Rapporteur on the Right to Health, Mr. Dainius Pūras; the then UN Special Rapporteur on the Rights of Persons with Disabilities, Ms. Catalina Devandas-Aguilar; and the UN Independent Expert on the enjoyment of human rights by persons with albinism, Ms. Ikponwosa Ero.

Endorsing the initiative, Mr. Pūras said:

> The COVID-19 pandemic and emergency measures taken by States around the world raise many challenges and concerns with regard to persons with disabilities, especially for those in residential care. Measures undertaken to stop the spread of the virus may increase risks that the human rights of these people are violated. In such situations, when closed institutions are becoming even more closed, the need for independent monitoring becomes more important than ever before.

In her endorsement, Ms. Devandas-Aguilar highlighted:

> The COVID-19 pandemic represents a threat to the lives of people with disabilities. COVID-19 is hitting hard in our community, feeding on and deepening the historical and structural discrimination against people with disabilities. Social care institutions, nursing homes and psychiatric facilities, where people with disabilities are often institutionalised or detained against their will, have become hotspots of the pandemic, accounting for half of the fatalities in some countries. Governments across the world must act fast to guarantee that all COVID-19 responses are accessible and disability-inclusive.

Ms. Ero emphasized the serious consequences of COVID-19 for persons with albinism:

> The COVID-19 pandemic is brewing a perfect storm that could facilitate violations for many people with disabilities who are subject to harmful practices; in particular, those with mystified or relatively rare conditions such as persons with albinism. Their situation, already precarious due to harmful stigma and physical attacks, is exacerbated by the closures caused by the pandemic. As many harmful practices increase in times of uncertainty and economic downturn, and are often perpetuated by relatives and friends, it is more important than before to ensure that national protection measures are inclusive of persons with albinism and others vulnerable to such harmful practices.

Launch and Methodology of the Survey

The Coordinating Group of the COVID-19 DRM conducted extensive online meetings during March and April 2020 to develop three related sets of questions quickly and efficiently concerning the impacts of COVID-19 and related state measures on persons with disabilities for different stakeholders. The surveys were jointly released on 20 April 2020.

The survey had three components, each targeting distinct categories of stakeholders. The first questionnaire requested official information from governments. The second targeted national human rights monitoring mechanisms, including National Human Rights Institutions (NHRIs), National Preventive Mechanisms (NPMs) under the auspices of the UN Optional Protocol to the Convention against Torture (OP-CAT), and national monitoring mechanisms and frameworks operating under Article 33 of the UN Convention on the Rights of Persons with Disabilities (CRPD). The third questionnaire targeted persons with disabilities and their families and representative organizations (organizations of persons with disabilities, OPDs).

The survey aimed to gather both quantitative and qualitative information on the experiences of persons with disabilities, on how states were responding or failing to respond to this specific population. To achieve comparability among the three categories, *core questions* were designed which were integrated across all three questionnaires, building on a set of core human rights guarantees agreed by the Coordinating Group. These questions covered the right to life, the right to liberty, the right to health, the right to live independently in the community, the right to access services, the right to accessible and appropriate information, and the right to access to justice. The responses to these core questions enabled the COVID-19 DRM to triangulate and compare responses between and among different categories of stakeholders.

The questionnaires also contained *additional*, *tailored questions* for each category of stakeholder. For example, national human rights monitoring mechanisms were asked whether they were continuing to visit and monitor institutions and group homes where persons with disabilities were detained and whether remote monitoring of abuses of persons with disabilities was taking place. Only persons with disabilities and their representative organizations and national human rights monitoring mechanisms were asked about whether penalties resulting from breaking state of emergency rules (fines, sanctions, arrest) were imposed on persons with disabilities or their personal assistants and carers.

Beyond this, the survey sought to highlight the experiences of persons with disabilities who are particularly marginalized, including those living in institutions, children, older persons, homeless persons, women and girls, and those who live in rural locations. To gain some level of disaggregation, questionnaires requested personal data such as gender, country of residence, and disability category. However, respondents had the option to withhold personal information and to remain anonymous.

The survey was translated into and published in 25 languages, including five official UN languages, namely, Arabic, English, French, Russian, and Spanish. The other 20 languages were Albanian (Shqip), Amharic, Bahasa Indonesia, Bangla, Bulgarian, Croatian, Czech, Dutch, German, Greek, Hungarian, Italian, Lithuanian, Maltese, Nepali, Portuguese, Romanian, Serbian, Slovak, and Slovenian. The questionnaires were mostly translated by volunteers.

The questionnaires were published on a specially designed website and were disseminated extensively through the Coordinating Group's international networks, social media, and direct outreach. In an effort to reach out to those persons with disabilities and OPDs with limited or no access to the Internet, print versions of the questionnaire were also made available. Throughout the research, all data was collected and processed in compliance with the European Union (EU) General Data Protection Regulation (GDPR).

The COVID-19 DRM survey employed a human rights-based approach at all stages, from planning, drafting, and dissemination through to data gathering and analysis phases. The Coordinating Group consciously centered the active participation of persons with disabilities and OPDs at all stages and maintained a strong grounding in international human rights law.

Data Collection and Analysis

The survey remained open from 20 April to 7 August 2020. During this period of 3.5 months, 2,152 individual responses were received from 134 countries around the world, representing over two-thirds of UN member states. Although the Coordinating Group distributed the questionnaires as widely as possible, only 26 responses were received from governments, and only 12 responses came from national human rights monitoring mechanisms, indirectly confirming the concerns of Coordinating Group members that states and national human rights monitoring bodies had not placed a high level of priority on the situation of persons with disabilities during the pandemic. The vast majority of responses came from persons with disabilities themselves and their family members and OPDs, enabling the COVID-19 DRM to frame a global picture of the personal experiences of persons with disabilities during the first wave of the pandemic.

The data gathered through the survey is presented on a visual data dashboard on the COVID-19 DRM website (https://covid-drm.org). The data can be filtered by type of respondent and by country. Furthermore, responses can be filtered by using the keywords "children" and "institution." An interactive map makes it easier to get access to basic information about countries from which responses were received, and there is a function enabling comparison across different countries.

The questionnaires contained both open- and closed-ended questions, making it possible for the COVID-19 DRM to gather large sets of qualitative and quantitative data. The quantitative data were analyzed using Microsoft Excel. The qualitative data coming from responses to open-ended questions provided often vivid depictions of the lived experiences of persons with disabilities and the impact of COVID-related measures implemented by states. In total, the survey received over 3,000 testimonies in different languages, and non-English responses were translated into English mainly by using Google Translate. These testimonies were then coded and analyzed.

The quantitative data were examined in light of the qualitative data, and an inductive research approach was adopted to identify key themes, subsequently providing the structure for a final report which was published in October 2020 (Brennan et al., 2020). The four themes were (i) the inadequacy of measures to protect persons with disabilities in institutions; (ii) breakdowns in the provision of community support; (iii) disproportionate impacts on underrepresented populations of persons with disabilities; and (iv) denial of access to healthcare.

Demographic Profile of the Respondents

In total, the survey received 2,152 responses from respondents in 134 countries, representing the single largest global effort focused on collecting data concerning the impact of the pandemic on persons with disabilities. Of these, 1,325 respondents identified themselves as female, 695 identified as male, and 92 identified as others or did not disclose. Eight hundred sixty-three responses were received from persons with disabilities, 525 responses from OPDs, 448 responses from family members of persons with disabilities, and 276 responses from others, including people working in services and institutions for persons with disabilities.

The largest number of responses (943) was received from persons self-identifying as having a physical impairment from whom 943 responses were received. Five hundred twenty-four responses were received from persons with intellectual impairments and their advocates. Four hundred forty-seven responses were received from persons with psychosocial disabilities and their advocates, 418 from deaf persons and their advocates, 403 from persons with autism and their advocates, 388 from blind persons and their advocates, 351 from persons with Down's syndrome and their advocates, 348 from persons with hearing impairments and their advocates, and 161 responses from deafblind persons and their advocates. These statistics are all based on self-identification.

In terms of geographical scope, the highest number of responses (225) was received from Germany. One hundred thirty responses were received each from Italy and France, followed by 105 from Austria, and 94 from the United States. The highest level of responses from the African continent came from South Africa (83), while the highest number of responses in Central and South America came from

Mexico (73). From Asia, India was the country with the highest number of responses, from which 50 responses were received.

Findings of the Survey

In this subchapter, we address the human rights violations persons with disabilities reported to have experienced during the COVID-19 pandemic. First, we provide findings drawing on quantitative data collected through the survey, and then we provide a selection of testimonies received from persons with disabilities and their families and OPDs.

The high level of responses and global spread of respondents made it possible to identify cross-cutting themes. One of the stark conclusions was that persons with disabilities worldwide had experienced similar barriers, restrictions, and direct impacts of state measures concerning the pandemic, including across countries of vastly different levels of socioeconomic development. Consistent concerns were raised by persons with disabilities that they had either been left out of national response efforts or that they felt completely abandoned by public authorities who had failed to implement disability-sensitive or disability-inclusive responses. Beyond the thematic analysis described above, the richness of the datasets enables focused analysis of specific human rights guarantees.

Violation of the Right to Life of Persons with Disabilities

Responses to the survey support the conclusion that large-scale and small-scale institutions became hotbeds of infection during the early stages of the pandemic, resulting in large numbers of deaths of persons with disabilities resident in such facilities. Nearly a quarter (486) of the total number of respondents to the third questionnaire, which targeted persons with disabilities and their families and OPDs, said that their government took no measures to protect children with disabilities in residential schools. Furthermore, 22.5% (476) of the total number of the respondents to the third questionnaire said that their government took no measures to protect the lives, health, and safety of persons with disabilities in institutions. Sadly, respondents also explained that the right to life of persons with disabilities in the community was also insufficiently protected.

Respondents from around the globe reported that governments did not put measures in place to prevent or control the spread of COVID-19 in institutions. More precisely, respondents reported that governments did not take sufficient steps to safeguard the right to access food, basic medical supplies, and personal protective equipment or to implement measures (such as social distancing) in order to minimize infections and deaths in institutional settings. The COVID-19 DRM received testimonies indicating that deaths in institutions could have been prevented by immediate, emergency government measures. The COVID-19 DRM also received responses that many deaths could also have been prevented in the community, particularly had access to life-saving treatment for COVID-19 been guaranteed. Sadly, respondents reported that access to basic and emergency treatment, including for COVID-19, was instead discriminatorily denied to persons with disabilities.

A survey respondent with disabilities in Canada described the situation with these words:

> [Institutions] were dangerously understaffed, and there were people dead in their beds, others laying on the floor, and some others with three layers of diapers and dehydrated.

Another respondent with disabilities from the same country said:

> The government of Nova Scotia refuses to consider that there is any issue with care in the community and ignores any examples to the contrary. We have people in our community dying of neglect, but the province will not accept the fact that their deaths are related to covid b/c their care was terminated due to covid-19.

A respondent from a Ugandan organization of persons with disabilities said:

> I know two PWDs who have been shot at because they were outside in curfew time. These were deaf people and didn't know what was happening.

Another respondent with disabilities from Nigeria shared with the COVID-19 DRM that as a consequence of the total lockdown of an institution, people were *effectively imprisoned*. According to this respondent:

> A lot of people died because of this.

Violation of the Right to Liberty and the Right to Live Independently and be Included in the Community of Persons with Disabilities

Of those respondents who stated that they were aware of the situation in institutional settings for persons with disabilities, 69% (819) said that residents of such facilities were restricted or banned from leaving the institutions. A further 84% (1,172) said that the government had banned or restricted visits from family, friends, or others to social care facilities. Eighty-two percent (984) of those who knew reporting being aware of the situation in psychiatric health facilities said that their government had banned visits.

Deprivation of liberty in institutions for persons with disabilities has been a long-term concern of disability rights advocates, but the spread of COVID-19 has exacerbated the situation and brought heightened levels of awareness of the inherent dangers in congregate living settings. The very low numbers of responses received from national human rights monitoring mechanisms indicate that residential institutions were cut off from the rest of society, without any independent monitoring mechanisms in place. When residents presented with COVID-19 symptoms, they reported being quarantined and isolated. A particularly telling example is the November 2020 collective complaint under the European Social Charter *Validity v. The Republic of Finland* on the violation of the rights of persons with disabilities in institutions during the pandemic (European Committee of Social Rights, No. 197/2020).

The survey received responses from family members of persons with disabilities and OPDs expressing grave concerns for the safety and well-being of their family members within institutions. A Greek OPD described psychiatric institutions as:

> hermetically sealed with more absolute restrictions than before, with no possibility of visits, with no advocacy services and with no independent monitoring.

Similarly, a Bulgarian OPD reported that while the implementation of lockdowns on institutions might prevent infection:

> it is also a measure that can lead to a lack of care, lack of transparency and concealment of dangerous abuses.

According to an Australian OPD:

> The government has taken a very 'hands off' approach to group homes, hostels and larger institutions, allowing those residences to self regulate how they respond to the crisis. A lot of people are now 'locked in' with all visitors suspended including community access, medical professionals and families.

Similar lockdowns were introduced in institutions for children with disabilities. A person with disabilities in Belgium reported:

> From what I know, children in institutions are strictly confined, can no longer have contact with their families. They are really imprisoned while the providers bring the virus. Very significant mental consequences.

Violation of the Right to Health of Persons with Disabilities

The right to health includes many aspects, and the right to access to healthcare, including access to treatment for COVID-19, is of prime significance to persons with disabilities in the context of the pandemic. A clear finding of the survey is that persons with disabilities reported being denied access to healthcare on an equal basis with others on a discriminatory basis. The COVID-19 DRM received more than 550 written testimonies worldwide regarding problems in accessing to healthcare. These testimonies suggest that persons with disabilities experienced discriminatory triage policies and denial of access to essential healthcare and medication.

Forty-five percent (958) of the total number of respondents to the third questionnaire said that people in their country could not access therapies, and a further 43.4% (918) said that people in their country did not have access to rehabilitation. Over

30% (641) of the total number of respondents to the third questionnaire reported problems in accessing medication during the pandemic. Furthermore, 37.8% (799) of respondents complained that their government had taken no measures to ensure that persons with disabilities could access specialized medical care.

In relation to lack of access to healthcare, a person with disabilities from Colombia said:

> The very low level of accessibility to health services, which do not have the corresponding reasonable adjustments, and in the case of Deaf people, they have not been able to provide the sign language interpreting service either virtual or in person.

Discriminatory triage guidelines were addressed by a large number of respondents. According to one testimony, a Canadian child with autism was denied a test for COVID-19:

> because the attending physician deemed him too difficult to assess. He had all the symptoms of Covid-19 but was refused confirmation.

An OPD from the United Kingdom put it this way:

> A eugenics programme has been undertaken covertly... Do Not Resuscitate Notices (DNRs) were placed on people with no consultation, especially older persons and persons with learning disabilities.

Many respondents highlighted that persons with disabilities living in institutions did not receive appropriate medical treatment for COVID-19, and in some cases hospitals directly refused to treat residents. A French pointed out the discriminatory character of triage policies adopted in relation to people with disabilities in institutions:

> The SAMU (Urgent Medical Aid Service) and the care services in the event of infection with Covid-19 have explicitly said to no longer come to institutions. Hospitals have issued recommendations for triage of patients, which said to leave them in an institution.

The COVID-19 DRM received some testimonies from staff members concerning the position of people with disabilities who were left inside institutions and experienced enhanced restrictions on their liberty. Respondents reported that residents were overmedicated, sedated, or locked up. An OPD from Andorra reported:

> self-harm has occurred and the solution by the institution has been overmedication.

Regarding access to medication, a person with disabilities from Zimbabwe said:

> To get medicine is not easy in my community, pharmacies demand United States Dollars which the majority don't have and the medicines are very expensive beyond the reach of many persons with disabilities.

Violation of the Right to Accessible Information of Persons with Disabilities

Almost a third (621) of the total number of respondents to the third questionnaire said that persons with disabilities did not receive sufficient information about how to protect themselves from infection with COVID-19. Furthermore, 21.2% (448) of the same respondents shared that information about COVID-19 was not available in accessible formats. With regard to closed settings, 322 respondents to the third questionnaire said that persons with disabilities living in institutions were not even informed about declarations of a state of emergency, about bans and restrictions on visitors, nor about how to protect themselves from COVID-19. The lack of information was mentioned in relation to specific types of information, including preventive measures, lockdown rules, testing and treatment, and access to social assistance schemes. In terms of the qualitative data, 345 testimonies were received concerning access to information during the pandemic.

Some respondents were concerned that persons with disabilities did not have access to information when they were hospitalized. An OPD from Hong Kong said:

> Insufficient information has been released by the government or the information released was not in any accessible format to the deaf and hard-of-hearing community. [. . .] the official sign language interpreters assigned REFUSED to show up at the hospital in this crisis.

The lack of access to accessible information was reported to be a problem in the community as well. An OPD from Lesotho shared with the COVID-19 DRM:

> No measures have been taken to inform persons with disabilities about the virus especially in areas where such individuals can't access information through radio or television.

Similarly, a person with disabilities from India highlighted:

> There isn't enough information available to what is happening to persons with disabilities, the lockdown is making it impossible to step out and access information. It can be said that information is just not available either to or about persons with disabilities in this situation, on a public or general level. Few things have been put up online at relevant govt portals but most persons with disabilities have no access to these staying in institutions. Perhaps they don't even know what is going on outside!!

The experience of a person with disabilities from Canada is this:

> Information provided is all from an able-bodied perspective and ignores the disability experience.

An OPD from the Republic of North Macedonia reported:

> All information from the media is not in accessible formats. Beside the press conferences that are made in sign language, all other information is not in accessible formats.

An OPD from India shared with the COVID-19 DRM:

> There are no specific measures to address the issues of persons with disabilities. Lack of information in accessible formats. No specific assistance.

A person with disabilities from Uganda said:

> The government has not done anything in particular to help people with disabilities during this period of Covid-19. In fact, we have been left out. The information is not adequate since no sign language interpreters have been allocated.

Violation of the Right to Freedom from Violence, Neglect, Exploitation, and Abuse of Women and Girls with Disabilities

The COVID-19 DRM survey received 25 written testimonies addressing violations of the right to freedom from violence, neglect, exploitation, and abuse, including sexual assault, domestic violence, and concerning police brutality against women and girls with disabilities. Although respondents raised concerns about police harassment, intimidation, and violence as a result of strict enforcement of curfews in general, women and girls were reported being disproportionately affected due to the failure of states to take targeted protective measures. Respondents reported that the COVID pandemic had exacerbated the pre-existing high levels of violence faced by women and girls with disabilities and, in some cases, had given rise to different forms of gender-based violence.

A number of respondents from Kazakhstan, Namibia, Nepal, Nigeria, Rwanda, Uganda, and Zimbabwe noted significant increases in cases of gender-based violence, including rape.

An OPD from Nepal reported:

> Recently, a girl child aged 10 years who lives with intellectual disability has been raped. Hence the government should take measures.

Women and girls with disabilities experienced violence from the police too, for example, when they went to seek food and were left in the situation of being forced to break curfew rules. An OPD from Nigeria said:

> A mother of a child with Cerebral Palsy was harassed by policemen on her way to collect food relief at one of the distribution centers.

Similarly, an OPD from Uganda reported:

> Women with disabilities have undergone violence of their rights. A woman with disability was beaten up after curfew time. She was looking for food.

Domestic violence has been on the increase during the pandemic. A respondent from Zimbabwe said:

> Since the lockdown women with disabilities just like any other women have been facing domestic violence and the government has not made any (special) provisions for women with disabilities in order to protect them.

An OPD from Uganda pointed out:

> Domestic violence is on the increase during this period, and this placed PWDs at higher risk too.

An OPD from Kazakhstan shared with the COVID-19 DRM:

> With the locking down the city and its infrastructure (so, even people were not allowed to go outside for a walk, only for grocery and emergency case) many people were facing domestic violence. I think since social workers were not allowed to visit homes this issue went out of control.

A respondent from Rwanda highlighted:

> My biggest concern is that since the pandemic and subsequent lockdown, cases of gender-based violence have increased and although this issue is affecting every woman, girl and child, it is doubly affecting women and girls with disabilities but due to the lockdown they may not be able to report these cases.

Violation of the Right to Education of Persons with Disabilities

Almost a third (623) of the total number of respondents to the third questionnaire said that their government took no measures to protect the health and safety of children with disabilities in institutions, including those in residential schools and in respect of those in the community. Furthermore, 41% (867) of the same respondents said that their government had taken no measures to support families of children with disabilities during the pandemic.

The findings of the survey revealed that children with disabilities did not have access to education worldwide since they were often excluded from remote learning, as well as due to lack of access to technology. For example, a person with disabilities from the Republic of Moldova said:

> Children with disabilities did not have access to online education due to lack of information technologies and internet access.

A person with disabilities from the United Kingdom reported:

> There is no help for adapting to distance learning education, particularly for children with mental health, ADD, autism, etc., where the challenges are often behavioral rather than access to info. Parents are abandoned and need help.

A respondent with a disability from Vietnam highlighted:

> There is a serious shortage of equal opportunities for PWDs in education, employment, and many others.

The COVID-19 DRM received numerous testimonies from families of children with disabilities. For example, a family member of a person with a disability from Canada said:

> We are being denied the right to access education. While nothing is normal at the moment the plan to continue educating children without providing the necessary supports to children with disabilities means they are left behind unable to access education. [. . .] children cannot access online education independently and is not conducive to supporting them.

Indicative of the multiple challenges faced by children with disabilities and their families, the family member of a person with a disability from Ireland reported the following:

> We have been left to work it out ourselves, the only support is a community phone line we can ring. Financially we have been left and therapy workers have been moved to the frontline and so we are without therapeutic support, education support is non existent, home support is gone. We are very much on our own.

A family member from the United States shared this with the COVID-19 DRM:

> Families of children with disabilities have been left behind in this situation. With the transition to online learning, most children with disabilities have not received the educational instruction needed. Teachers have done a great job but have not been given the support they need to provide the education needed.

Violation of the Right to Adequate Nutrition and Food for Persons with Disabilities

More than 30% of respondents were concerned about the lack of access to food and nutrition. Serious problems were reported from all around the world including the highly developed countries as well as from low-resource states. The COVID-19 DRM received 131 testimonies concerning aspects including a lack of access to food, having less food because of increased food prices, and limitations on diet, such as only having access only to canned food. The findings of the survey revealed that persons with disabilities in remote and rural areas faced additional barriers to accessing food and nutrition.

One person with disabilities from Kenya said:

> They have not yet come to the ground to provide basic needs like food to people with disabilities. They only do it in the major cities. Even those in the streets are still suffering.

A respondent from India shared the following information about closed residential settings:

> Institutions have been locked down as a measure to prevent contamination. However, the lockdown has created problems like scarcity of food supplies and basic essentials.

In relation to lockdown policies, an OPD from Nepal said:

> The government announced the stay at home order and lockdown, but could not think of poor daily wage earners who are not getting even a meal a day. People are deprived of food and are in financial crisis and the government has not provided any benefits.

According to an OPD from Pakistan:

> Persons with disabilities are stuck at homes because of lockdowns, they need specific services and food for survival, they are not provided food items during distribution, limited people get food bags but persons with disabilities have no access to get food bag from government or private point.

And further concerning the impact of lockdowns, a Ugandan OPD said:

> There is no access to food and financial support due to lockdown in homes.

Respondents from countries with high levels of development also reported serious problems with accessing food and nutrition. For instance, a person with disabilities from Canada said:

> Food insecurity is always an issue, as is increasing rents. Now, I'm finding it impossible to survive, because I always relied on store sales to buy food, soap, and toilet paper, and there are simply no sales to be found.

A respondent with disabilities from Australia reported:

> My main concern is that the living expenses of all people with disabilities have gone up, and continue to go up, and the Australian government insists that they haven't. Many of us are getting to the point of missing meals altogether, choosing between food or medication, etc. We're finding out the hard way just how negative the government's attitude is towards people with disabilities, and our collective moral is very low as a result.

A respondent with disabilities from the United States said:

> Typical services used by PWDs [persons with disabilities] to maintain independence are now being used by others. Grocery delivery usually available that day, now not available for 5–6 days. I cannot go to the store in my power wheelchair without typically available transportation. I am forced to eat canned and processed food, which is high in salt, and dangerous for my health.

According to an OPD from the United Kingdom:

> We understand that many disabled people were unable to access food deliveries as they were not in the high-risk groups.

Violation of the Right to Community-Based Services for Persons with Disabilities

More than a third (777) of the total number of respondents to the third questionnaire said that their government took no measures to protect the life, health, and safety of persons with disabilities living in the community. Thirty-five percent (742) said that their government took some measures and only 12% (207) said that their government took significant measures. Many persons with disabilities felt that they were abandoned and that essential community-based services were not available for them during the first wave of pandemic. For example, 38.3% (809) of the total number of respondents to the third questionnaire said that persons with disabilities did not have access to personal assistance. 33.5% (708) said that persons with disabilities did not have access to informal care in the community, meaning that essential support generally received from family members, community members, and friends were severely curtailed. 28.6% (604) said that persons with disabilities did not have access to home-based support.

In those countries where persons with disabilities did have access to community-based services before the pandemic, respondents reported that access to these services was almost completely suspended following the imposition of public health restrictions. Together with those countries where such services were rarely available prior to the outbreak, respondents reported that the situation of persons with disabilities became life-threatening. For example, a respondent with disabilities from Mongolia said:

> DPOs [Disabled People's Organisations] are complaining there's no support and operations to families with PWDs [persons with disabilities] in their home.

An Italian respondent with disabilities shared:

> I am afraid that my mum will die of exhaustion and then I will die without her assistance.

A person with disabilities from the United States shared the following:

> Social distancing has become the norm, but getting usually gotten community support [is] nonexistent.

Persons with disabilities in Canada reported:

> I have not seen or been able to access any additional support or information.
>
> The government has not taken any measure at all to support PWDs [persons with disabilities] living in the community.

A person with disabilities from New Zealand said:

> Isolation is their only solution but this does not work for those needing community supports to maintain independent living if you have no family or friends to rely on, and many community services were removed from people's lives quickly as lockdown began.

OPDs and family members of persons with disabilities shared similar concerns. For instance, an OPD from Zimbabwe said:

> We are still waiting for the support schemes but nothing tangible. We are now on a second lockdown and the first one we never received assistance.

An OPD from Trinidad and Tobago pointed out:

> I am not aware of any special measures being taken for persons with Down Syndrome. Social service support is focused on special areas.

Another OPD in South Africa was concerned about a lack of mental health services in the community:

> Mental health services which are community based are not available, this put beneficiaries at risk of relapse.

A family member of a person with disabilities from the United Kingdom said:

> I have removed my son from all day services and respite provisions but have received very little in support. Two phone calls and no offer of any extra support for us at home. We've been left to get on with it.

Impact of the Survey

From an early stage of implementation, members of the Coordinating Group recognized the crucial importance of engaging in ongoing and coordinated advocacy to respond to issues as and when they were emerging in connection with the survey. During the data collection phase, the Coordinating Group published three statements which were widely circulated concerning the serious issues emerging inside residential institutions worldwide (COVID-19 DRM Coordinating Group, 2020a); significant numbers of reports of violence and abuse at the hands of police and security forces, including due to the strict enforcement of lockdowns (COVID-19 DRM Coordinating Group, 2020b); and the catastrophic breakdown in provision of food, nutrition, medicine, and other essential supplies (COVID-19 DRM Coordinating Group, 2020c).

Already by early April 2020, initial members of the COVID-19 DRM had written to the Director-General and regional directors of the WHO requesting information concerning the collection of disaggregated data regarding persons with disabilities and COVID-19, as well as information and guidance being produced for states. A response received 2 months later did not directly address the data questions but welcomed the efforts of the Coordinating Group to establish the COVID-19 DRM. The WHO is reliant upon states collecting and reporting such datasets, but it was apparent that there had been no concerted action to develop information collecting and reporting protocols about the situation of persons with disabilities, leaving the COVID-19 DRM to fill a crucially significant gap.

Prior to publication of the final report, the Coordinating Group was also able to report on emerging themes and priorities at the international level. In August 2020, the UN Committee held a virtual session, during which the COVID-19 DRM Coordinating Group was invited to present multiple written and oral briefings (Allen, 2020). The Chairperson of the Committee reflected concerns of the Coordinating Group in his closing remarks at the session:

> [The] pandemic had exacerbated the pre-existing exclusion against persons with disabilities, both those living in their communities as well as those still in institutions. Measures to contain the pandemic had curtailed persons with disabilities' access to basic services in the community. These measures had reportedly broken pre-existing support for persons with disabilities in the community, including support measures and personal assistance[. . .]. The Committee also received allegations of different forms of violence against persons with disabilities, including gender-based violence. Particularly worrying was the reported violence by law enforcement officers in a number of countries[. . .]. It was appalled by accounts indicating the lack or ineffectiveness of measures to safeguard the right to life of persons with disabilities throughout the pandemic period (UN Office of the High Commissioner for Human Rights, 2020).

Expressing serious alarm about the emerging findings pointing to institutions as hotbeds of contagion, the CRPD Committee resolved to establish a working group to support deinstitutionalization, including in the context of emergencies, with international consultations planned to take part in 2021 (UN Committee on the Rights of Persons with Disabilities, 2021).

The findings of the survey and final report were released at a high-profile online event attended by over 300 participants worldwide on 22 October 2020. The event featured testimonies from persons with disabilities from Europe, Latin America, Africa, and Asia, as well as interventions from members of the Coordinating Group. The event also included responses from a wide range of international experts, including the newly appointed Special Rapporteurs on the Right to Health and on the Rights of Persons with Disabilities, a representative of the World Health Organization, and a representation of the Global Alliance of National Human Rights Institutions (GANHRI).

The findings of the survey have been publicized internationally and have been widely cited by international experts (see, e.g., Quinn (2020)), disability rights activists, and more recently mainstream international media (see, e.g., Al Jazeera (2021)). The authors are also aware of some efforts by the WHO to place a stronger focus on developing tools to assist states in collecting disaggregated data on the basis of disability in the context of its work under the International Health Regulations (World Health Organization, 2008).

Proposed Recommendations

The Coordinating Group of the COVID-19 DRM proposed recommendations to the CRPD Committee and to state parties in its joint submission for consideration at the 23rd Session (resumed) of the Committee on the Rights of Persons with Disabilities (Allen, 2020) and to decision-makers in the COVID-19 DRM global report "Disability rights during the pandemic" (Brennan et al., 2020). These recommendations included:

(i) Calling on all relevant stakeholders to take concrete measures to protect the rights to life, health, freedom from all forms of abuse, inclusion in the community, and education in ongoing recovery and response efforts.
(ii) Enactment of emergency plans for deinstitutionalization, including immediate measures to prevent new admissions into residential settings in the context of the pandemic.
(iii) Ensuring immediate access to essential supplies, foods, and medicines.
(iv) Guaranteeing nondiscriminatory access to healthcare and removal of discriminatory triage procedures.
(v) Enhancing the direct involvement of persons with disabilities in response and recovery plans on a systematic basis.
(vi) Strengthening the availability and accessibility of information.

At the time of drafting, it was not yet possible to assess the extent to which states and other actors had begun to act on the outcomes of the COVID-19 DRM. Nevertheless, the study provides a clear and concrete baseline from which members of the Coordinating Group and others can assess progress as the world continues to grapple with this ongoing international emergency.

Conclusion

The COVID-19 DRM was the largest and most comprehensive effort to collect information concerning the impact of the pandemic on persons with disabilities, as well as the effects of related state measures. The initiative was developed rapidly by a wide range of organizations of persons with disabilities and disability rights advocates to respond to a perceived and actual failure on the part of international organizations and states to collect such data in real time. Indeed, this lack of data collection is both symptomatic and causal of a lack of responsiveness to the disproportionate impacts of the pandemic on persons with disabilities.

Disability rights advocates are strongly aware of the limited public significance placed on issues of policy concerning persons with disabilities. An important tool in the box is independently organizing, monitoring, and responding to the actions (or inactions) of key duty bearers. Explicitly grounding initiatives such as the COVID-19 DRM in human rights norms transforms the quality of advocacy, moving the focus beyond the direct humanitarian consequences of public emergencies, instead proceeding to frame recommendations grounded in binding international obligations. The unprecedented nature of the pandemic forced unprecedented speed and scale in order to provide a meaningful picture which could positively contribute to making during the first wave and to inform ongoing emergency response and recovery operations.

The fact that such an initiative was necessary in the first place should give us pause for consideration. Now 1 year into the pandemic, increasing evidence is emerging tending to confirm the findings of the COVID-19 DRM, showing with remarkable consistency that persons with disabilities have not merely been disproportionately affected but are in fact substantially overrepresented in terms of mortality and infection and are bearing the brunt of longer-term consequences of the deadly disease. The warning signs of these impacts were identifiable even during the early stages. The surveys confirmed many of the fears of persons with disabilities and advocates and point to a truly concerning level of serious consequences worldwide. Despite the commitments of global leaders to "Build Back Better," very few have taken concrete steps on the basis of the body of evidence, including the findings of the COVID-19 DRM, that the pandemic has acutely affected people with disabilities in every country in the world. Despite the concerted advocacy of OPDS, including the Coordinating Group, institutions continue to be locked down in many countries, policy-makers continue to make discriminatory decisions which deny people with disabilities access to healthcare, and few responses and recovery plans are sufficiently grounded in protecting human rights.

The COVID-19 DRM was implemented entirely by the partners on their own initiative and within their limited existing means, stretching the capacities of the partners in ways never before experienced. We are proud of what we could achieve with such limited resources but nevertheless would take greater pride if and when states sit up and declare that protecting the rights and lives of persons with disabilities is a genuine priority and act on it.

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Independence and Its Meaning: ENIL's Monitoring of Article 19 as a Struggle for Hermeneutical Justice

41

Teodor Mladenov

Contents

Abstract

This chapter explores the efforts of disabled people's independent living movement to negotiate the meaning of independence. It focuses on the work of the European Network on Independent Living (ENIL) – a user-led, user-controlled initiative of disabled people and independent living organizations that has led the fight for independent living in Europe since 1989. I conceptualize ENIL's monitoring of the implementation of Article 19 of the Convention on the Rights of Persons with Disabilities (CRPD) as a struggle for hermeneutical justice. ENIL has challenged the conventional understanding of independence as self-sufficiency. This conventional understanding has undermined disabled people's right to live independently and be included in the community. In its stead, ENIL has promoted an understanding of independence stemming from the independent living movement and incorporated in Article 19 of the CRPD. According to this alternative understanding, independence means that one has choice and control in one's everyday life, including choice and control over one's support – rather than coping without support. This alternative understanding of independence has guided ENIL's monitoring of deinstitutionalization reform and personal assistance schemes in Europe that are discussed in the chapter as instances of disabled people's organized collective struggle for hermeneutical justice.

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Introduction

For disabled people, as for other oppressed groups, negotiation of meaning is often a power struggle against social hierarchies and for individual and collective emancipation. A central element of this struggle has been the contest over the meaning of independence. In the modern period, independence has been understood predominantly as the ability to cope on one's own, without external support (Mladenov, 2016). Medical and other "helping" professionals have reproduced this understanding in their treatment of disabled people. Professionals have put their efforts into fixing disabled people's bodies and minds so that disabled people become independent by becoming self-sufficient. Those who could not be fixed in this way have been confined to residential institutions or their homes (Oliver & Barnes, 2012).

The one-sided interpretation of independence as self-sufficiency is hermeneutically unjust. Hermeneutical injustice is a kind of epistemic injustice defined by the philosopher Miranda Fricker (2007: 158) as "having some significant area of one's social experience obscured from collective understanding owing to hermeneutical marginalization." The conventional understanding of independence as self-sufficiency obscures the experiences of interdependence that underpin self-sufficiency. Historically dominant groups such as men and abled-bodied people have benefitted from this obscurity because the infrastructures of interdependence have privileged them. For example, feminization of care has privileged men while obscuring their dependence on women's caregiving (Fraser & Gordon, 1994); and ableist building conventions have privileged walkers while obscuring their dependence on environmental adaptations such as stairs (Oliver, 1993). Similarly to women, disabled people have historically been prevented from challenging the one-sided interpretation of independence as self-sufficiency due to hermeneutical marginalization – their oppression has prevented them from participating on equal terms in meaning-generating practices such as research and policy-making (Oliver, 1992).

Women have been able to overcome their hermeneutical marginalization by engaging in collective action for individual and social change. A key instance of such collective mobilization has been the activity of consciousness rising through peer support. The practice of group "speak outs" has helped to awaken "hitherto dormant resources for social meaning that brought clarity, cognitive confidence, and increased communicative facility" (Fricker, 2007: 148). As a result of such collective hermeneutical efforts, women were able to overcome taken for granted interpretations of their experiences and "to realize resources for meaning that were as yet only implicit in the social interpretive practices of the time" (Fricker, 2007: 148).

A similar rise in "cognitive confidence" and "increased communicative facility" leading to realization of new "resources for meaning" occurred among disabled people when they started speaking out among themselves about their experiences of institutional care and their desire to have more choice and control in their everyday lives (Evans, 2002). Eventually, this gave rise to a new social movement.

The disabled people's independent living movement emerged in the late 1960s and early 1970s in the United States, spreading quickly to other parts of the world in the subsequent decades (DeJong, 1979; Evans, 2002; Ratzka, 1993). The movement has opposed the segregation of disabled people in institutions for social care and has advocated for personal assistance and other forms of user-led, community-based support that enable disabled people's full and equal participation in social life. A central part of this activism has consisted in challenging the one-sided understanding of independence as self-sufficiency, imposed on disabled people by medical and other "helping" professionals, service providers, policy-makers, public administrators, and the wider society. In this way, the independent living movement has initiated a process of rectifying a hermeneutical injustice suffered by disabled people. Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) has been an important milestone in this struggle.

In their fight for hermeneutical justice, the activists of the independent living movement have insisted that independent living is not about self-sufficiency. It is not about one's ability to cope on one's own, without external support. Rather, independent living is about choice and control in one's everyday life that, importantly, includes choice and control over one's own support:

> Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation. Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbors and friends take for granted. (ILI, n.d.: n.p.)

In its General Comment No. 5 on Article 19 of the CRPD, the Committee on the Rights of Persons with Disabilities (2017: 4) concurs: "Independent living is an essential part of the individual's autonomy and freedom and does not necessarily mean living alone. It should also not be interpreted solely as the ability to carry out daily activities by oneself."

The spread of the independent living movement in Europe resulted in the creation of the European Network on Independent Living (ENIL) in 1989 by a group of visionary disabled activists (Evans, 2002: 13–14). Since then, the organization has served as a user-led, cross-disability forum for disabled people, independent living organizations, and their non-disabled allies on the issues of independent living. Currently, ENIL has 72 full and 42 associate member organizations from more than 40 countries, most of them in Europe but some in Asia and Africa (see https://enil.eu/about-enil/our-members/). ENIL's mission is to advocate and lobby for independent living values, principles, and practices such as the provision of personal assistance, deinstitutionalization, barrier-free environment, and adequate technical aids. The organization is financially supported by the European Commission, the Open Society Foundations, and its Nordic allies in Norway and Sweden.

ENIL has joined disabled people's struggle for hermeneutical justice by creating its own definitions of independent living and kindred disability policy concepts such as personal assistance, deinstitutionalization, and community-based services (ENIL, n.d.). These definitions have been based on ENIL's monitoring, research, and advocacy work and have incorporated the testimonies and lived experiences of ENIL's members. They have been adopted by ENIL's Board in 2012 and since then have been actively disseminated and promoted by the organization. ENIL's definitions have been aligned with Article 19 of CRPD, and their aim has been to guide and enable the monitoring of disability policies on European and national levels. They have also been used to clarify misunderstandings and to prevent the hijacking of the language of independent living advocates:

> The terms 'independent living' and 'personal assistance' have often been exploited and misused to profit organisations, charities and disability business which are not run and controlled by disabled people. These organisations do not appear to want to fully understand the concept of independent living as developed by the independent living movements across Europe and internationally. (Jolly, 2009: 2; see also Angelova-Mladenova, 2017: 11)

In addition to guiding and overseeing the deployment of the independent living discourse in Europe, ENIL has monitored the implementation of Article 19 of the CRPD by collecting and assessing country-specific information about the translation of independent living concepts into social policy practices. The organization has systematically gathered and analyzed data on deinstitutionalization reform and development of personal assistance schemes as key areas of Article 19's implementation. I will first discuss ENIL's definition of independent living and then present the organization's work on deinstitutionalization and personal assistance. My analysis will be guided by Fricker's (2007) concepts of hermeneutical injustice and hermeneutical marginalization because the struggle over the meaning of independence has been a central concern of the independent living movement and, by extension, of ENIL's work.

Before proceeding, a note on my positionality. Although I have not yet identified as disabled, I have been involved in the independent living movement since 2000, and I consider myself an ally. In the period 2000–2009, I did action research and advocacy work for the Center for Independent Living - Sofia, and in 2017–2019, I was Marie Curie Individual Fellow at ENIL, where I was funded by the European Commission to conduct research on personal assistance in Europe. I am currently based in Scottish academia, at the University of Dundee, where I maintain close links with the independent living movement through my continuing collaboration with ENIL that has included the writing of this chapter. The views presented here are my own, but they have been informed by my work with ENIL, and my colleagues at the organization have been consulted on and support this account of ENIL's monitoring and advocacy.

ENIL's Definition of Independent Living

At the heart of ENIL's work is its understanding of independent living that has been captured in a definition (ENIL, n.d.). In order to pay heed to the significance of this definition for the organization's struggle for hermeneutical justice, I will discuss it here statement by statement. ENIL's definition begins by suggesting that independent living is about the implementation of rights-based policies, in concert with Article 19 of the CRPD that frames independent living as a human right: "Independent living is the daily demonstration of human rights-based disability policies" (ENIL, n.d.: n.p.). In disability studies and activism, the rights-based approach to disability policy has sometimes been opposed to the needs-based approach, and the shift from "needs" to "rights" has meant a transition from charity to entitlement, from passivity to activity, and from professional domination to self-determination of disabled people (Oliver, 1996: Ch. 5). Indeed, the CRPD has been described on its official website as an embodiment of precisely such a hermeneutical shift by taking:

> to a new height the movement from viewing persons with disabilities as 'objects' of charity, medical treatment and social protection towards viewing persons with disabilities as 'subjects' with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society. (United Nations, n.d.: n.p.)

The second statement of ENIL's definition of independent living makes the point that independent living policies pursue two strategies simultaneously, in combination: "Independent living is possible through the combination of various environmental and individual factors that allow disabled people to have control over their own lives" (ENIL, n.d.: n.p.). The first strategy is to design or modify mainstream environments – including buildings, housing, transportation, schools, and workplaces – to make them accessible and accommodating for disabled people. The creation of specialized services such as sheltered workshops or day-care centers, even when physically located within the community rather than on its margins, does not enable independent living but perpetuates segregation and exclusion (Angelova-Mladenova, 2017: 12). Instead of such services, independent living requires personalized support in the community that includes personal assistance, communication assistance, and assistive technologies, among others. These solutions comprise the "individual factors," the second policy-making strategy that makes independent living possible.

ENIL's definition then emphasizes that disabled people should be able to make "choices and decisions regarding where to live, with whom to live and how to live" (ENIL, n.d.: n.p.). This point suggests that independent living excludes housing and servicing arrangements where disabled people are forced to live in designated buildings and groups, as well as to follow everyday routines determined by service providers or disabled people's "helpers." In policy terms, housing and support should be decoupled – otherwise, "people who need support are forced to accept a ‘group home’ type living arrangement, and vice versa – people who need a place to live are forced to accept the support provided there” (Angelova-Mladenova, 2017: 26). This is crucial when considering ENIL’s fight over the meaning of deinstitutionalization, discussed below.

Independent living calls for redistribution of resources toward universally available and accessible services (positive measures), as well as for non-interference and respect of privacy (negative measures) – support should not be imposed through hard or soft power but freely chosen through informed consent: “Services must be available, accessible to all and provided on the basis of equal opportunity, free and informed consent and allowing disabled people flexibility in our daily life” (ENIL, n.d.: n.p.). Together with being universal and consensual, support should be flexible – its opposites are the rigid routines and one-size-fits-all solutions of residential institutions and other provider-led services (Evans, 2002). This point will be revisited in the discussion of ENIL’s monitoring of personal assistance schemes.

The fifth statement of ENIL’s definition of independent living iterates the environmental factors and the individual factors that make independent living possible: “Independent living requires that the built environment, transport and information are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services” (ENIL, n.d.: n.p.). Finally, since independent living is a human right, support for it should be unconditional rather than restricted by identity categories or degree of needs: “It is necessary to point out that independent living is for all disabled persons, regardless of the gender, age and the level of their support needs” (ENIL, n.d.: n.p.). Here, we find a response to the common critique that the independent living movement prioritizes physically disabled people of working age (Westberg, 2010: 14–15) – rather, independent living is meant to be universally applicable, as also stated in Article 19 of the CRPD.

In sum, ENIL’s definition of independent living suggests that independent living is a human right that requires both mainstream adaptations and personalized solutions in which housing and support are decoupled and which are universal, consensual, flexible, and unconditional. From this perspective, to be independent means to have unrestricted access to mainstream environments and personalized support that is organized in such a way so that one has maximum choice and control in one’s everyday life. This understanding of independence excludes institutional care and rectifies the hermeneutical injustice suffered by disabled people when independence is one-sidedly interpreted as the ability to cope alone, without external support, or to be self-sufficient. To overcome their hermeneutical marginalization and to assert their own understanding of independence, disabled people have organized in a social movement and have set up organizations such as ENIL.

ENIL’s Advocacy for Deinstitutionalization

The fight against disabled people’s segregation in residential institutions has been a hallmark of the independent living movement since the time of its inception (DeJong, 1979; Evans, 2002; Ratzka, 1993). Institutions have been exposed by the members of the movement and their allies as sites of abuse and oppression that have deprived their residents of choice and control in their everyday lives. In concert with this struggle, Article 19 of the CRPD has been oriented toward challenging and preventing institutionalization by asserting the right of all disabled people "to live in the community, with choices equal to others." Subparagraph (a) of Article 19 clarifies that this right presupposes "the opportunity to choose their place of residence and where and with whom they live on an equal basis with others." Since the 1960s, first in North America and Europe and later in other parts of the world as well, there have been various policy responses to institutional horrors and injustices that have been subsumed under the general heading of "deinstitutionalization" (Mladenov & Petri, 2020).

ENIL (n.d.: n.p.) has defined deinstitutionalization as "a political and a social process, which provides for the shift from institutional care and other isolating and segregating settings to independent living." The organization has advanced deinstitutionalization reform in Europe in a number of ways. Since 2008, ENIL has managed the European Coalition for Community Living (ECCL) – a Europe-wide initiative that has promoted community-based services as alternatives to institutional care (Parker & Bulic, 2010). ENIL has also been an active member of the European Expert Group on the Transition from Institutional to Community-based Care (EEG) – a coalition of advocacy organizations, international bodies, and service providers established in 2009 and supported by the European Commission to guide deinstitutionalization in the European Union (EU). As part of this collaboration, ENIL has led the development of two highly influential reports on deinstitutionalization that have had a significant impact on deinstitutionalization policies at EU level (EEG, 2012, 2014).

ENIL has also monitored the use of the European Structural and Investment Funds (ESIFs) for projects ostensibly committed to deinstitutionalization in EU countries. ESIFs have been the main financial instrument used by the European Commission to help and/or nudge EU member states toward developing their economies and welfare systems in sustainable and socially just ways (European Commission, n.d.). ENIL has monitored the use of ESIFs by collecting and assessing country-specific information on deinstitutionalization reform, which has resulted in a number of reports and policy briefings (e.g., Parker & Bulic, 2010, 2013; Parker et al., 2016). In gathering evidence, ENIL has prioritized the testimonies of disabled people and their local organizations. Thus, rather than confining its monitoring to legal and policy analysis, ENIL has relied heavily on evidence generated on the ground by its members and stemming directly from the lived experience of disabled people. This has been a defining feature of ENIL's monitoring and has differentiated its policy work from that of other international organizations that have relied on expert fact-checking missions to develop their reports. Since 2016, ENIL has been doing this work in the framework of its EU Funds for Our Rights campaign, financially supported by the Open Society Foundations (Bulic & Kokic, 2018; Parker et al., 2017).

At the heart of these campaigning and monitoring activities, one finds a fierce hermeneutical struggle over the meaning of deinstitutionalization, which overlaps with the more general struggle over the meaning of independence. In Europe, deinstitutionalization reform has routinely been framed by the most powerful stakeholders in the process – service providers, policy-makers, and big disability charities – either as a renovation of the old, large residential institutions or as a relocation of residents to newly created smaller institutions (Mladenov & Petri, 2020). These smaller setting such as small group homes, even when better resourced and placed within communities, have nevertheless reproduced key features of institutional life such as lack of control over one's assistance, rigidity of routine, bloc treatment, paternalistic approach to provision, and surveillance (for a comprehensive list of such features, see Committee on the Rights of Persons with Disabilities, 2017: 4–5).

In addition, the providers of segregated services have appropriated the language of independent living to serve their own ends by claiming that their settings are "independent living institutions" – for example, by offering training in "independent living skills" (Jolly, 2009: 2–3), more appropriately described as training in "daily living skills" (EEG, 2012: 128). Such appropriations have been criticized by independent living activists as misuse and misrepresentation of the concepts developed by the independent living movement (Jolly, 2009: 3). In its General Comment No. 5 on Article 19 of the CRPD, the Committee on the Rights of Persons with Disabilities (2017: 4) has also stated that neither large-scale institutions nor smaller group homes can be called "independent living arrangements" if they deprive their residents of choice and control in their everyday lives through rigid routines, bloc treatment, surveillance, and other practices characteristic of institutional care.

ENIL's hermeneutical struggle over the meaning of deinstitutionalization has been a central aspect of its monitoring of the use of ESIFs. The organization has repeatedly asserted that according to EU regulations, guidelines and reports, ESIFs should be used to promote independent living and inclusion in the community, in concert with Article 19 of the CRPD – accordingly, ESIFs should not be invested in building new residential institutions or renovating the existing ones, except in life-threatening circumstances and as part of ongoing efforts at deinstitutionalization (Parker et al., 2016: 43). To rectify the hermeneutical marginalization of disabled people in interpreting and assessing deinstitutionalization initiatives, ENIL has advocated for the inclusion of disabled people's organizations in the monitoring of deinstitutionalization programs (Parker et al., 2017).

Hermeneutical marginalization of disabled people has led to flawed deinstitutionalization. ENIL's monitoring of ESIFs has revealed that many countries have used ESIFs to maintain and renovate institutional settings and/or to build new institutions under the heading of "deinstitutionalization" (Parker & Bulic, 2013). Most (although not all) of the cases of such misuse of ESIFs identified by ENIL have been located in newer EU member states in Central and Eastern Europe, including Croatia, Czech Republic, Bulgaria, Hungary, Romania, Latvia, Lithuania, Slovakia, and Slovenia (Bulic & Kokic, 2018: 9–10; Parker & Bulic, 2013). These countries have strong traditions in institutionalization of disabled people, inherited from their state socialist past – although state socialism disintegrated in the region at the end of the 1980s, its legacy of institutional segregation has continued to shape disability policy over the following decades (Mladenov & Petri, 2020: 1206–1208). One way to maintain the status quo of segregated provision has been to interpret the creation of smaller institutions as deinstitutionalization:

> We have received numerous reports of plans to replace large residential institutions with small group homes and similar residential facilities, as well as with foster care for disabled adults. While these services may be located in the community, they perpetuate the segregation and social exclusion of disabled people by failing to provide disabled people with the opportunity 'to choose their place of residence and where and with whom they live on an equal basis with others' [as stipulated in Article 19 (b) of the CRPD]. ENIL is also concerned that Member States are not using ESI Funds to invest in mainstream services, such as housing, employment or inclusive education. (Bulic & Kokic, 2018: 7)

To summarize, interpreting deinstitutionalization as maintaining old or building new institutions is a case of hermeneutical injustice inflicted upon disabled people. In this process, powerful stakeholders such as service providers have imposed an understanding of the shift from institutional care to "living independently and being included in the community" (Article 19) that has served their own interests while depriving disabled people of choice and control in their everyday lives. ENIL has struggled to rectify this hermeneutical injustice by exposing the interpretations of deinstitutionalization propagated by the dominant disability policy actors as false. In its monitoring of the ESIFs, ENIL has sought to overcome the hermeneutical marginalization of disabled people in negotiating the meaning of deinstitutionalization by formulating and promoting an understanding of deinstitutionalization rooted in disabled people's independent living movement. According to this (still) marginalized understanding, effective deinstitutionalization requires access to housing, mainstream services, peer support, and personal assistance (ENIL, n.d.: n.p.). The next section focuses on personal assistance, which has been yet another site of fierce hermeneutical struggle for independent living advocates.

ENIL's Advocacy for Personal Assistance

The activists of the independent living movement consider personal assistance (PA) to be key for independent living (Ratzka, 2004). Article 19 (b) of the CRPD concurs by stipulating that the states parties should ensure access to PA in order to realize disabled people's right to living independently and be included in the community. However, the meaning of PA has been as contested as the meaning of independence and deinstitutionalization (Jolly, 2009; Ratzka, 2004). ENIL has been involved in this hermeneutical struggle by creating its own definition of PA. This definition identifies PA as "a tool which allows for independent living" and describes key features of PA such as cash allocations; provision on the basis of individual needs and circumstances; rates of pay that ensure adequate salaries for the assistants and cover additional expenses such as employer contributions, administration, and peer support; and, ultimately, the right of PA users to recruit, train, and manage their assistants (ENIL, n.d.: n.p.).

ENIL's definition of PA builds on previous efforts at defining PA from the perspective of the independent living movement (Ratzka, 2004). Such user-led initiatives have contested provider-led interpretations which have branded as "PA" support available only in kind and/or covering only a limited set of needs, with inadequate rates of pay and other restrictions – in essence, support that deprives its users of choice and control over recruitment, training, and management of their supporters. Independent living activists have insisted that provider-led, limited, conditional, and/or inflexible support schemes may amount to home care, or nursing, or companionship, but not PA (Westberg, 2010). By making such distinctions possible, ENIL's definition of PA has been a vehicle for the advancement of hermeneutical justice – it has provided hermeneutically marginalized people with a means to challenge interpretations of individually provided support that may actually restrict disabled people's choice and control under the guise of maximizing them.

ENIL has used its definition of PA to guide its monitoring of PA services in Europe, the outcomes of which have been presented in several reports (ENIL, 2013, 2015; Mladenov et al., 2019). At the beginning of the 2010s, ENIL conducted a study of PA that included desk research of existing national legislative provisions, as well as a survey among disability experts from 22 European countries about the availability and the characteristics of PA schemes provided in their countries (ENIL, 2013). In this study, experts from 14 of the countries in the sample reported on the availability of relevant legislation, but the characteristics of the services provided under the heading of PA varied widely, and in many cases, these characteristics were in contradiction with ENIL's understanding of PA. This analysis was updated in a follow-up study conducted in 2015 that identified lack of progress or deterioration of existing PA services:

> The challenges that PA users throughout Europe meet nowadays have not changed much since 2013. Disabled people are still fighting to receive more hours of assistance, better salaries for their assistants and access to PA regardless of the type of their impairment. One of the main reasons for these challenges is financial, but not less important is the difficult transition from the medical to the social model of disability. Changing the mindset of society and decision makers is a challenge that needs to be tackled persistently. (ENIL, 2015: n.p.)

More recently, in 2018, ENIL developed and implemented the PA Checklist (Mladenov et al., 2019). Similar to ENIL's previous two studies of PA, the PA Checklist was designed at ENIL specifically for assessing PA schemes from the perspective of independent living. The tool included a set of criteria informed by ENIL's definition of PA and corroborated by PA users and independent living advocates in a preliminary survey.[1] The PA Checklist was piloted in eight

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[1] The PA Checklist consists of 61 statements describing typical characteristics of PA which either enable or hinder the choice and control of PA users in their everyday lives. These characteristics were selected on the basis of a survey conducted among ENIL's members and subscribers of ENIL's newsletter during the initial stage of the project, in the period January–March 2018. The survey asked the participants to assign scores to a longer list of 138 characteristics of PA, formulated by the project leader based on literature review and consultations with colleagues at ENIL. The

European countries by local independent living experts who were also PA users. They were purposively selected by ENIL by considering their expertise in PA, and they were personally invited to assess PA schemes that they use and/or know well. Most of these experts have also participated in the development of the schemes they assessed. Based on their assessments, each PA scheme achieved an overall mean score, indicating the degree to which the scheme enabled or hindered users' choice and control. In addition to the overall scores, mean scores were calculated for five different dimensions of PA. Table 1 summarizes the results – more detailed information about the study is presented in Mladenov et al. (2019), where the PA Checklist is also included as an appendix. It should be noted that the specific information provided by the experts in their assessments has not been cross-checked or further verified, so it must be taken with caution.

The results from the application of the PA Checklist confirmed a key finding reported in the previous two studies of PA implemented by ENIL (2013, 2015). This finding concerns the sheer variability of support schemes identified (in some cases misleadingly) as PA in different European countries. The checklist provided a quick, easy, and quantifiable way of assessing and comparing support schemes parading as PA, and it did so from the (hermeneutically marginalized) position of the independent living philosophy. The mean scores presented in Table 1 allowed to judge at a glance whether a PA scheme conformed to a definition of PA created and supported by the members of the independent living movement in Europe. Thus, for example, the PA schemes available on the national level in Sweden and Serbia were assessed as highly compatible with this definition, whereas the PA schemes available on local level in Bulgaria and on national level in Ireland were assessed as incompatible. Instead of enabling disabled people's choice and control, the latter were actually suppressing them. Similar to flawed deinstitutionalization, flawed PA deprives disabled people of their independence.

ENIL has continued the work of monitoring PA schemes by launching its first Independent Living Survey in June 2020 (ENIL, 2020). The survey contains general questions about independent living and more specific questions about PA that draw on its previous two studies (ENIL, 2013, 2015) and the PA Checklist (Mladenov et al., 2019). At the time of writing this chapter, the results of the Independent Living Survey were still being analyzed. What is clear is that ENIL's latest study is yet another intervention in the negotiation of the meaning of PA. Through such interventions, ENIL has sought to advance hermeneutical justice in disability policymaking by asserting an interpretation of PA grounded in the experiences of disabled people who use support from others on an everyday basis.

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participants in the survey scored each characteristic of PA according to the degree to which they considered the characteristic to be enabler or hindrance to independent living. Of the 138 initial characteristics of PA, the 61 highest-scoring ones were included in the PA Checklist. An example of such a high-scoring enabler is "The users can keep their assistance when moving to another region or local authority within the country" and of a high-scoring hindrance: "Under the scheme, assistance is bound to a location (for example, it is provided only at the user's home)." The implementation and outcomes of the survey are reported in Mladenov (2019).

Table 1 PA checklist – summary (Reprinted from Mladenov et al., 2019)

Country, region	PA scheme (in local language in brackets)	Coverage[a]	Overall mean score	Mean score by dimension				
				Context	Funding	Needs assessment	Provision	Working conditions
Belgium, Flanders	Personal following budget (PVB Persoonvolgende budget)	Regional	**0.30**	−0.23	1.05	0.89	−0.94	0.73
Bulgaria, Sofia[b]	Assistant for independent living (Асистент за независим живот)	Local	**−0.71/ −0.91**	−0.69/ −1.30	−1.87/ −1.87	0.23/0.20	−0.05/ −0.24	−1.19/ −1.33
Ireland	Health service executive scheme	National	**−0.61**	−1.60	0.06	−1.32	−0.18	−0.03
Serbia	Personal assistance service (Usluga personalne asistencije)	National	**1.13**	1.98	−1.14	1.41	1.43	1.97
Slovenia	Independent living (Neodvisno življenje)	National	**1.03**	0.88	−1.14	1.73	2.05	1.64
Spain, Andalucía	Pilot project of independent living (Proyecto piloto Vida Independiente)	Regional	**0.03**	0.76	−1.87	0.52	0.98	−0.23
Sweden	Personal assistance direct payment (Assistansersättning)	National	**1.34**	0.64	1.87	0.18	2.08	1.96
United Kingdom[c]	Direct payment – Personal budget	National (local funding)	**−0.42**	−1.33	−0.43	−0.43	−0.02	0.10

Notes

[a] All of the PA schemes included in the sample are publicly funded, although levels (national, regional, local) and forms of funding vary (i.e., they can be annual, project-based, social insurance based, requiring users' contributions, including charity contributions)

[b] Two assessments were completed in Bulgaria by two experts who assessed the same PA scheme independently of each other. Therefore, the corresponding cells of the table contain two values for mean score each

[c] The UK assessment concerns the national policy of providing "direct payments" for PA as a whole, rather than any particular version of the policy implemented by a particular local authority

Conclusion

In this chapter, I conceptualized disabled people's advocacy for independent living as struggle for hermeneutical justice that has sought to overcome the hermeneutical marginalization of disabled people in meaning-generating practices concerning disability policy. These practices have traditionally been dominated by medical professionals, service providers, politicians, and others occupying positions of power in areas such as disability-related research and policy-making that have affected disabled people but have historically excluded them. Powerful disability policy actors have perpetuated a one-sided interpretation of independence as self-sufficiency – an interpretation whose reproduction has constituted a hermeneutical injustice inflicted on disabled people. The conventional understanding of independence as self-sufficiency has been so pervasive that even prominent disability studies scholars have reproduced it: "Dependence is the reality, and independence grandiose thinking" (Davis, 2002: 31). Independence is grandiose thinking only when interpreted one-sidedly as self-sufficiency.

This interpretation has been challenged by the independent living movement through an alternative interpretation of independence that has rendered independence in terms of choice and control in one's everyday life, including choice and control over one's support – rather than ability to cope without support. To iterate, from the perspective of the independent living movement, to be independent does not mean to cope without support or to be self-sufficient but to have access to support that is organized in such a way so that the person who uses this support has maximum choice and control in their everyday life.

This alternative understanding of independence has been incorporated in Article 19 of the CRDP, which represents a major – although not decisive – achievement in disabled people's struggle for hermeneutical justice. The achievement of Article 19 has been consolidated by the Committee on the Rights of Persons with Disabilities (2017) in its General Comment No. 5 that has interpreted Article 19 along the lines of the independent living movement. However, it has not been a decisive achievement because there is still a lot of work to be done in order to translate the meanings implied in Article 19 into actual disability policies. The domination of "helping" professionals and service providers in defining disability issues continues to be strong, and it takes an organized and consistent collective effort to articulate, maintain, and safeguard a truly transformative and emancipatory reading of the CRPD that is in line with the values and principles of the independent living movement (Mladenov, 2013).

In her analysis of hermeneutical injustice, Fricker (2007: 174) points out that hermeneutical marginalization results from unequal relations of power that exceed the domain of communication. The interpretation of independence as self-sufficiency is underpinned by material interests – most obviously, by the interests of providers of traditional services such as institutional care, who strive to maintain their competitive advantage over user-led, community-based alternatives. Hermeneutical injustice cannot be overcome by virtuous individual action alone – it is not enough that a decision-maker is willing to listen to the ideas of those who use services and to be convinced by their arguments or by their reading of Article 19 of the CRPD. The very structure of decision-making needs to change so that the members of the group whose interpretations have so far been marginalized become equal participants in meaning-generating practices. For this to happen, argues Fricker (2007: 174), collective political action is needed.

The work of ENIL represents such an organized collective effort at becoming an equal participant in the negotiation of meaning that guides contemporary disability policy. As a user-led, user-controlled initiative, ENIL has developed and promoted definitions of independent living and kindred disability policy terms such as deinstitutionalization and personal assistance that draw on principles and values espoused by the independent living movement. In this way, ENIL has advanced hermeneutical justice in disability policy-making in Europe and beyond.

ENIL's monitoring of actual deinstitutionalization and personal assistance policies has been part of this hermeneutical struggle. The organization has used its interpretation of independent living in order to expose as flawed "deinstitutionalization" programs that renovate institutions or move people to smaller institutions, as well as "personal assistance" schemes that effectively amount to home care. Such policies have been exposed as flawed because they do not maximize disabled people's choice and control in their everyday lives. ENIL has advocated for their substitution with policies of deinstitutionalization and personal assistance that reflect the meaning of independence elaborated by the activists of the independent living movement and incorporated in Article 19 of the CRPD.

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Disability Rights Monitoring in Practice: Applying Holistic Participatory Methodology

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Sonja Vasic and Emma Matreniuc

Contents

Abstract

This chapter is a short summary of the personal experience of participation in the Disability Rights Promotion International (DRPI) project in Europe by two women disability rights advocates with the living experience of disability. The DRPI project is a global collaborative project aiming to set up an independent monitoring framework using holistic participatory disability rights monitoring methodology. In doing so, it seeks to empower grassroots Disabled People's Organizations and to equip them with the knowledge and tools to monitor their rights. The authors explore the emancipatory potential of DRPI holistic participatory monitoring methodology, reflecting on their personal experience of involvement with the DRPI project in the region of Eastern Europe. With a time distance, they offer critical reflections on the advantages and shortfalls of DRPI methodology. Sonja was the trainer in the DRPI country monitoring

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training in Serbia, Bosnia & Herzegovina, and Moldova. She followed the process of elaborating country monitoring of holistic reports in these countries, which facilitated her understanding of the broader picture and thus her own endeavors in her country of origin. Emma was a participant in the DRPI country monitoring training and later conducted interviews with persons with disabilities and reported their experiences of human rights violations. She founded a non-governmental organization for young people with disabilities and presented Moldova's alternative report in Geneva. These developments considerably changed the situation in her hometown and contributed to the shift of perception of disability in Moldovan society as a whole.

Keywords

Disability rights · Monitoring · Participatory · Disability Rights Promotion International · UN Convention on the Rights of Persons with Disabilities

Introduction

The scope of this chapter is to give a short summary of the personal experience of participation in the Disability Rights Promotion International (DRPI) project in Europe[1] and to share some lessons learnt from the perspective of two participants with different backgrounds and roles in the DRPI project. We hope that by doing so, we could contribute to the process of capitalization on the experiences gained through the DRPI project in Europe and globally and to enhance the capacities of Disabled People's Organizations (DPOs) to monitor the implementation of the UN Convention on the Rights of Persons with Disabilities (UNCRPD). The DRPI project enabled us to compare the development of the life situation of persons with disabilities people with disabilities and the state of play of their human rights in different countries with regard to reporting on their national disability issues and to follow-up on the UNCRPD Committee's concluding observations sent to different countries. All of this facilitated our understanding of the broader picture and thus our own endeavors in recognizing which concrete actions in our countries could lead to good outcomes.

Worth noting in the introduction of this chapter is a little background information about the DRPI project before we move on to reflect on our personal experience and roles in the project and in the process of disability rights monitoring. DRPI is a global collaborative initiative that was set up to develop a holistic, participatory, and emancipatory methodology of disability rights monitoring. It was supported by the Swedish International Development Agency and led by York University of Toronto

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[1] Note that the DRPI country monitoring projects were implemented in more than 40 countries worldwide and that the DRPI operated through four regional centers: Europe, Africa, Latin America, and Asia-Pacific with the headquarters in Canada. See more about the structure and geographical coverage of the DRPI project at: https://drpi.research.yorku.ca/

under the auspices of its co-directors: Prof. Marcia Rioux and Bengt Lindqvist, former UN Special Reporter on Disability, who sadly died in 2016. The DRPI project rested on an emancipatory research paradigm equipping persons with disabilities with the knowledge and tools to monitor their rights instead of being mere objects of research and the source of information to other human rights experts and organizations. That being said, the holistic participatory methodology of disability rights monitoring was developed and used to build the capacities of national and local DPOs worldwide to monitor the implementation of the UNCRPD. The methodology was called "holistic" because it sought to gather data across three elements of disability rights monitoring: monitoring of individual experiences of persons with disabilities; systemic monitoring, which involved a review of national laws, policies, and regulations; and the monitoring of media reporting on persons with disabilities (Rioux et al., 2016, 2019; Rioux, 2017).[2] It was deemed "participatory," because DRPI provided training and capacity building[3] for national and local DPOs that wanted to engage in the monitoring process so that they could be the ones to conduct all phases and elements of holistic monitoring, collecting data on human rights violations of their peers and reporting on them, and using such evidence for advocacy to advance social changes in their local contexts.

Sonja's Experience with the DRPI Project

As a former Handicap International (HI) staff member in the South East Europe (SEE) region, it was natural for me to accept the role of the trainer in DRPI country monitoring training in three countries (Serbia, Bosnia and Herzegovina, and Moldova) and to support and follow up further processes of elaborating country monitoring holistic reports in these countries and the country of my origin, Montenegro. It was at that time that the UNCRPD was freshly ratified by the countries of the region. For us, activists in the disability movement, the ratification of the UNCRPD was a big step forward, welcomed by all the stakeholders in the region as the beginning, but with no clear vision of how to grasp the opportunity. The DRPI project was a privilege and lucky synchronicity for me to become quickly familiar with the monitoring as a sophisticated tool and probably the most demanding and also the most refined way of advocating the human rights of people with disabilities. The knowledge gained thanks to the DRPI project enabled me to compare the development of the life situation of people with disabilities in different countries with regard to reporting on their national disability issues and to follow-up the UNCRPD Committee's concluding observations sent to different countries.

The opportunity to summarize the impact that collaboration with the DRPI project had on me on a personal level and for the monitoring process of human

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[2] See also the DRPI website with more information on the holistic approach to disability rights monitoring: https://drpi.research.yorku.ca/disability-rights-monitoring/

[3] Complete DRPI training and the accompanying training materials are available on the online training platform, which was set up during the last phase of the DRPI project in 2016. See more at: https://drpitraining.research.yorku.ca/

rights of people with disabilities in Montenegro, which is the country of my origin and citizenship, came in summer 2020 through communication with the former DRPI Regional Officer for Europe, Mr. Rados Keravica (editor of this section of the volume). The reason for accepting his call to make a recapitulation of the experiences I had during joint country training on disability rights monitoring aimed at DPOs in the SEE region as part of the DRPI project in the period 2011–2013 was mostly based on my conviction that these activities were beneficial for my own understanding of the monitoring itself as a successful advocacy tool in the endeavors of people with disabilities to fight against discrimination, inequality, and in achieving better conditions in all aspects of people with disabilities lives. I wanted to capitalize on and share what I have learnt through this experience and to give some input into the continuation of using DRPI methodology and refining training materials.

My first contact with the DRPI project happened in 2011 during the regional training in Serbia from 26 April to 4 May. The organizers of that event were the Centre for Society Orientation (COD) and the Serbian Society of Autism, national disability organizations who were hosting the DRPI project and its regional center for Eastern Europe. COD was first established to take on project activities run previously by HI when the organization withdrew from the SEE region. COD inherited links with DPOs which were built between DPO regional movement and former Handicap International Regional Office in South East Europe. In the first decade of the twenty-first century, HI SEE led a very successful regional SHARE-SEE Project[4] aimed mainly at capacity building and empowerment of DPOs. The training in Serbia was organized to build the capacities of 30 DPO representatives from Serbia, Bosnia and Herzegovina, Croatia, Macedonia, and Montenegro in the field of human rights monitoring of persons with disabilities by introducing the DRPI methodology of holistic monitoring. The trainer was Mrs. Marcia Rioux (DRPI Co-Director). The DRPI project's concept was to first organize the regional training to make DPOs familiar with DRPI monitoring methodology and to set up national DPO coalitions, which would engage together in CRPD monitoring. Setting up the partnership and cross-disability coalitions was one of the main goals of DRPI methodology in order to provide for the unified voice of the movement. That was not an easy task and was challenging owing to existing issues surrounding disability politics within the national disability movements. Once the idea of working in a partnership was accepted, fundraising was set up together to ensure the funding for country monitoring projects. This is how the funds were secured later on (from various international donors and development agencies) for DRPI country monitoring projects in Montenegro, Serbia (both supported by DRPI and SIDA), Bosnia and Herzegovina, and Moldova and North Macedonia. I was invited by the regional host organization COD to join the trainers' team in delivering country training in Bosnia and Herzegovina (B&H) in 2012. The country training in B&H was organized in cooperation with the nongovernmental organization (NGO) MyRight – Empowers

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[4] Share SEE is an acronym for self-help, advocacy, rights, and empowerment.

People with Disabilities local office in B&H (previously known as Swedish organisations of disabled Persons international Association (SHIA), with whom I have already cooperated).

The training gathered representatives from several DPO coalitions active across all parts of B&H. In November 2012, I joined the trainers' team engaged in leading the country training in Moldova, hosted by the "MOTIVATIE," a leading DPO and service provider for persons with disabilities in Moldova. Prior to that time, I had no contacts or insight into the Moldovan disability community.

Finally, I was a member of the trainers' team that led the country training in Serbia in 2013, which was hosted by COD. The training workshop for the monitoring of rights of people with disabilities was held, with the participation of 28 participants – persons with disabilities from 14 different DPOs.

In the continuation of DRPI activities in Europe, I took an active part in writing the first Serbian holistic monitoring report (Keravica et al., 2013) and was the author of the Serbian media monitoring report. For the purposes of the report on media monitoring, articles in the print media in the period from September 2012 until June 2013 were analyzed, covering the topics of the rights of persons with disabilities. Nine hundred (900) articles from 53 printed media that appeared during this period were processed.

In 2015/2016, I went on my expat mission with HI, this time in Central Asia. Coming back to Montenegro in 2016, I continued to be active in the disability movement as a freelance consultant and disability expert, and I had a clear overview of the processes with regard to monitoring of the human rights of persons with disabilities in Montenegro. I trained local DPO representatives, those of the social protection sector, educational staff, media, and local authorities' representatives in monitoring the rights of persons with disabilities in the course of several training sessions during the period 2017–2021. My recent focus is on the gender-based multiple discrimination of women and girls with disabilities in Montenegro through involvement in a project supported by the American Consular Representative Office in the capital Podgorica.

Emma's Experience

My name is Emma Matreniuc, I am a person with reduced mobility, from the Republic of Moldova. My main profession is foreign languages lecturer, most of the time communicating and teaching various groups of people. At the same time, I am the founder of a nongovernmental organization VIVERE for people with disabilities, actively promoting the rights of people, dealing with issues such as accessibility, discrimination, diversity, acceptance, and participation for all in social and cultural life.

Back in 2013, I was living in the capital of Moldova, working as a university teacher, and facing a lot of difficulties as a person with reduced mobility. That was connected mostly with transportation and accessibility to infrastructure. Unfortunately, I did not know any terminology and rules or laws that could assist, understand, and promote PwD rights. My only help came from colleagues and friends who assisted me when I needed it. In the university where I worked, with the same non-existent accessible conditions as in the rest of country, the only thing the administration could do was to offer me a room to deliver my lectures on the same floor, so that I wouldn't have to go up and downstairs. That was a period when I was desperately looking for information and possibilities for studies or work connected with the domain of disability. Somehow, accidentally, I found an internet announcement about an upcoming training course about DRPI and about human rights monitoring. That was a starting point for me because I immediately decided to apply and was invited to participate. During the training, I felt extremely happy, for various reasons: first of all, from the very beginning it was a well-thought out, informative, and instructional course that touched many domains, such as cultural, political, but tightly connected with disability. Second, I felt very comfortable in that a huge number of people with various types of disability from different corners of my country, with whom we made acquaintance and became colleagues and friends forever. That made me feel much more confident that there were more people of the same mindset and that could be an important cornerstone for my personal and public goal. Moreover, the trainers who delivered the seminars proved to be great specialists who managed to give a considerable amount of information, explain the details of our upcoming work, and construct the sessions in such a way, that more and less experienced participants could become part of that big group, with no one left behind.

In the beginning, when the participants gathered, within several sessions, it became clear that all of them had a different level of knowledge, from some specific issues to special skills in one or another professional field and held different views about disability as a notion and phenomenon. That was a real educational course that included many different points to be learnt: models and approaches to disability, law and juridical issues, administrative aspects, personal attitudes, human rights, psychological aspects, lobbying and advocacy,, etc. This process also included concrete guidelines and instructions on how to travel through the country and organize interviews with our peers – people with disabilities. We also learnt the aspects of psychological, intercultural, language, national, and intrapersonal approaches to interviewing as a qualitative research method. There were certainly difficulties connected with the lack of basic information among a number of participants, but with the thorough and detailed explanations delivered by the trainers, there was a considerable improvement and leverage of needed information. There was another group of participants, who were from the fields of activities, partially connected with the sphere of disability, such as social workers or the members of those few organizations who by that time had already been active. However, monitoring activities in the field were a real starting point and implementation of the knowledge received at the training.

Talking about lessons learnt, I would like to mention that it introduced many new and important issues connected with the sphere of disability. Even if I am a PwD myself, the entire process of travelling in my country, looking for and getting connected with many other people with disabilities whose existence I did not know of, opened up a horizon for me and somehow outlined the way I wanted to do things in the future. To be more precise, the work of monitoring, communicating with people with disabilities, seeing and observing their behavior, conducting the interviews, and writing my small reports made me want to found an NGO that would promote the rights of people with disabilities. At that moment, another important discovery was that people with disabilities constitute a large category of people in our country and that monitoring was just the beginning of another grandiose approach. That was my personal feeling and attitude, which throughout the entire process had transformed into the desire to continue that path even after the project was over.

I had at that period gone through my personal development and learnt the strategies of lobbying and advocacy, which later helped me to work. At the same time during the training, I found out that a holistic approach to all the work and reporting was a core issue both at that moment and for the next period of life, where many of the other participants and myself started to work deliberately and consistently in this domain. I am convinced that that was a starting point that changed our attitude on a personal, local, and national level.

Among the issues we learnt was the approach of working in collaboration, connection, and cooperation. That became a focal point for both work on monitoring and as a follow-up to this monitoring process.

Insights from the Ground: Value, Effectiveness, and Challenges of DRPI Holistic Methodology of Human Rights Monitoring

DRPI Promotes a Holistic Approach to Monitoring

Sonja, Montenegro

I witnessed that the DRPI holistic approach to disability was in line with the previously promoted principles with regard to approaching disability in the region. A similar approach was mainly supported by the disability international donors and organizations that were actively present in the region (UN agencies, Save the Children UK,HI, SIDA – SHIA, Embassies, EIDHR, EU funds, EDF – Project CARDS, etc.). The added value of the DRPI project was a strong focus on the monitoring of human rights, which, as a tool, was a little neglected in the early phases of the empowerment of the DPOs in the region (which started in the late 1990s and the first decade of the twenty-first century). The fact that the strongest DPOs in each country of the former Yugoslavia were mainly oriented toward the social model of disability and a rights-based approach, was favorable for the implementation of the model proposed by the DRPI project. Moldova was also very receptive to DRPI methodology in spite of my low expectations before arriving there and facing the real situation. The monitoring of human rights is a challenging and demanding process and only high-profile DPOs were capable of internalizing and using it successfully in advocating for the rights of persons with disabilities and other causes they were oriented toward. One of the challenges that I identified as a trainer during working with DRPI original training material was that it was prepared for participants with an average level of familiarity with the human rights concept.

Those with a more advanced level had a feeling that their previous experiences were not sufficiently respected by the trainers and those with less experience were overwhelmed with the quantity of information to be digested in a short time. That is why I would prefer to conceptualize DRPI initial country training as the training of trainers. SHARE SEE had very good results, with a cascading approach to transferring knowledge in the SEE region. After a group of domestic trainers were trained by international trainers, the next cycle of training was led by the local trainers in their own countries and at the end of the process, the information about the methodology reached the broader public. This approach is empowering both in the field of gaining knowledge about monitoring but also with regard to good training and presenting skills within DPOs.

Emma, Moldova
As a participant in the training that took place in my home country, Moldova, there is an important moment to mention. It was during a period when the rights of people with disabilities had just started to be paid attention to. The ratification of the UN CRPD in Moldova had been a hot issue for discussion and started to be implemented very slowly. Thus, all the work and activities in terms of training that we received were due to the time and conditions in which our country had been at that moment. If we bear in mind those conditions, it is worth mentioning that there was a deeply entrenched medical approach toward people with disabilities, that presupposed a well-known vision as if those are sick people, with diseases, curable or not, but definitely not able to work, to be a part of society or participating at any activity or leading independent lives they wanted. Thanks to the implemented DRPI project and through the sessions delivered by the experts from Serbia and Montenegro, we learnt that people with disabilities could also be the experts of their lives, not only living it. Taking into account that people with disabilities are considered to be the biggest minority group, the DRPI project opened up the space to discover yourself as a citizen and as a person with disability who is doing something considerable and significant in his/her community, town, and country. Thanks to this project and the long sessions we had, there were opportunities to learn a lot of notions, ethical rules, historical background and examples from other countries and other people with disabilities, and the disability movement as a whole. This knowledge contributed to the success of the subsequent process of disability rights monitoring, including the interviews with our peers with disabilities we conducted with an aim to collect data and evidence of human rights violations in our country.

DRPI Promotes the Empowerment of Persons with Disabilities to Become the Leading Force of the Change

Sonja, Montenegro
First, talking about my own awareness, the DRPI project definitely improved my perception of the functioning of the system of human rights protection in general and about CRPD monitoring specifically. It also gave me a practical roadmap for follow

up the oscillation in enjoying the concrete effects of the legislative changes, the improved media depiction of disability, and to research the situation of persons with disabilities in my country. My recent engagement in assessing the situation of girls and women with disabilities in Montenegro is strongly based on interviews with girls and women and their family members and inspired by the Middle East adaptation of DRPI methodology led by the organization Stars of Hope.[5]

My experience is that all three countries targeted by country monitoring training succeeded in creating the Holistic Country Monitoring Report. It is a document that comprises all the results of monitoring components according to DRPI methodology (monitoring individual experiences, systemic analysis, and media monitoring) and is the final product of the monitoring processes conducted in one country where the project was implemented. The Country Monitoring Report is elaborated by the representatives of the DPO coalition at the country level and is the joint product of all the field workers, monitors, country coordinators, site coordinators, partner organizations at the national level, and the Regional DRPI Officer.

Participating DPOs in all three countries were later leaders in drafting shadow reports of their countries and presenting them in front of the CRPD Committee in Geneva. However, my opinion is that it would be very beneficial if DRPI training were offered simultaneously to non-disability human rights organizations and other compatible actors in targeted countries in order to facilitate the strong cooperation of different stakeholders. This could facilitate the creation of one high-quality and united shadow report, which was not the case in Montenegro, where two shadow reports were reported, one formulated by DPOs and the other one by human rights nongovernmental organizations. In general, I would be happier to see strong alliances between DPOs and other human rights defenders and their joint involvement in capacity-building activities and later activities in the field. That is why I see DRPI Project continuation in Montenegro as a combination of several strong links between DPOs and academia (for example, York University from Toronto, Canada, which led and coordinated the DRPI project and the Faculty for International Studies in Podgorica or other disability studies scholars and their universities), leading national human rights NGOs (for example, CEDEM[6]) and governmental monitoring bodies (for example, Monstat,[7] a parliamentary HR body). The financial support could come from government funds, which on an annual basis supports DPO projects aimed at fighting discrimination of people with disabilities and the promotion of equality. Of course, the individual interviews and monitoring of individual experiences of people with disabilities should stay exclusively in the hands of persons with disabilities themselves. Peer relationships could be more suitable for developing the relationship of trust and to mitigate the imbalance of power that might be evident between "expert" researchers and disabled people when treated as objects of

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[5] See more about DRPI's work in the Middle East at: https://drpi.research.yorku.ca/mid-east-news-3/

[6] See more at: www.cedem.me

[7] See more at: www.monstat.org

research. To mention the model of good practice, the Government of Montenegro adopted in 2016 the Analyses of compatibility of regulations in Montenegro with the Law on Prohibition of Discrimination of Persons with Disabilities and the UN Convention on the Rights of Persons with Disabilities, together with recommendations for harmonization. The document contains overall analyses of the Montenegrin legislation and covers 13 areas of legal regulation in almost 60 laws. The document was formulated by the working group in which representatives from the Government, Parliament, disability movement, human rights sector, Organization for Security and Co-operation in Europe (OSCE), and European Commission (EC) took part in the process whereas the text itself was elaborated by an expert.

Emma, Moldova
DRPI monitoring objective for that time was to organize interviews of people with disabilities also effectuated by other people with disabilities and that was precedence in our country. Its value was in the fact that people with disabilities were unexpectedly, for themselves and for the whole of society, taken out of their usual conditions, their context of life, their comfort zone, and literally from their homes. To my mind, that was a real breakthrough. Its value was to open up many issues that had been covered under the ash of history and society's attitude and maybe because of attitude of people with disabilities to themselves as well. During the training, several questions occurred: what is it to be a person with disability? What does the life of a PwD look like in our small country? The stereotypical approach, outdated and dry thinking and a vision through the prism of pity – all these and many other factors brought to the surface all the vices and clichés. Some of them for instance are: people with disabilities are poor, sick, and intellectually weak, cannot get a profession, should stay at home, do not earn money, cannot create a family or have no friends, are extremely vulnerable, have no good taste or cannot admire art or science, etc. We discovered at some point that people with disabilities are rights-holders, but in reality, they do not enjoy the same rights as others. It became obvious and sad at the same time, that disability is a label, a stigma, and it leads to isolation. It seems to be a voluntary exile.

After the training, as we approached the challenges of the entire process, it should be admitted that it was really tough. First of all, none of the participants had ever been in the role of the human rights monitor or an interviewer or have a tangential occupation or education in the given domain. Second, it was the first time that such a big number of people with disabilities from different regions of the country, various organizations, of different age, gender, profession, occupation or nationalities had gathered together for one objective. However, at that moment, people with disabilities were interested in learning something new that they had never done before. That was one of the first challenging moments.

From my personal observation, I have to admit, that was my first experience in participating in the activities organized by and for people with disabilities in my country. Moreover, the activities organized within the DRPI project were a novelty for all the participants and for the whole of society as well. I am also convinced that it moved the minds of many people and made a considerable shift in the understanding of what disability actually means.

Personal challenges had been faced while the real interviews took place. Even during the first stage, while recruiting and looking for the lists of people, talking and discussing with them about the eventual meeting – that was all new and unusual work. However, I have to admit that, personally for me, it had a profound impact and I founded an NGO for young people with disabilities and began a new path in my life and career as well. These things changed the situation in my hometown considerably and the attitude of the entire society as well. And for many other participants in the project, all the steps undertaken became the equivalent of deep life changes, vision, a decrease in negative attitudes including internalized ones, acceptance, breaking the stereotypes, environmental barriers, social and juridical knowledge, information, and it led to the liberation and desire to live further and in a different way, make the social changes that we are hoping for and to live fully as all other people without disabilities live.

So, talking about DRPI value in terms of methodology and the steps undertaken, as well as the total inclusion of people with disabilities, we can surely confirm that the monitors – the people with disabilities themselves – managed to understand all the procedures and to engage in disability rights monitoring for the first time in their lives. We practiced an elaborate procedure and the interviewing strategies before we started the fieldwork and we simulated interviews between ourselves in a group before we went in the field to interview others. It helped a lot to understand how the data collection of human rights violations works, what reactions we might expect, and how to handle all the challenges that we might face during data collection.

DRPI Promotes Solidarity and Networking of DPOs

Sonja, Montenegro

Speaking about the level of activity of disability movements, in the SEE region, the activism of DPO members varies across and within the organizations. More active members profile themselves and sooner or later the process of stratification inside the organization starts. The pool of people with disabilities or parents of children with disabilities who are providers of knowledge and skills become leaders and those people with disabilities who are at the receiving end are left behind. Inside the very same DPO field, we have the antithesis of the model that DRPI is promoting. Persons with disabilities, members of DPOs are often passive recipients of support rather than activists and resource persons positioned to emancipate others. Emancipation is a really long-term goal, and it takes time to achieve broad mobilization of people with disabilities to fight coordinately for their rights. To mention the model of good praxis, I would stress that high quality Montenegrin Shadow Report to UNCRPD, which was presented in Geneva in 2017, was mainly drafted by the persons with disabilities, members of DPO Youth with Handicap of Montenegro- UMHCG. The content of this Alternative Report had serious influence on the Concluding Observation of UN Committee on the Montenegrin Initial Report on UNCRPD.

Last, the level of DPO coalitions, the cross-disability approach is not fully put into practice in the region. Disability politics is mostly based on competition over access to scarce funds but also over better positioning in regard to the decision-makers. In the DRPI training material, the importance of working in coalitions should be covered more extensively, exposing the key challenges of disability politics within the movements.

Emma, Moldova
After founding the DPO VIVERE, I managed to get connected with other active NGOs and to gain more knowledge through active participation, self-study, and various projects. We concentrated our attention on accessibility in the entire northern region of Moldova, delivering seminars and personalized support. Thus, from a simple university lecturer, I transformed my life into a synergy of teaching and human rights promotion. I also started to work in the domain of inclusive education, travelling through the region and promoting accessibility in educational institutions, at polling stations, in all the other places. During my tenure as the NGO founder and director, collaborating with both beneficiaries and decision-makers, my commitment became to demonstrate exceptional service and professionalism in the domain of disability along with teaching, educating, and coordinating the communities and people with different needs and aspirations. Such synergy brings results in terms of interdisciplinary work and a multidimensional view on human rights and diversity, applying innovative techniques and approaches, creating a proper environment for persons with disabilities. All these had become real because of that DRPI training where I learned about disability rights for the first time, a training that literally taught people with disabilities to respect their rights, to be stronger, and to be grounded in knowledge, rules, the UN Convention, and human rights approach. In recent years, many people with disabilities got jobs, started to be more visible, became local counsellors in their communities, and actively participated in political and social life. We can openly and easily talk and voice different issues, no longer being afraid that our status as disabled persons will be the reason for us to be discriminated against or humiliated. That monitoring experience brought visible results and pushed forward many issues that had been covered under society's fear and lack of awareness of the role and rights of people with disabilities. The knowledge we acquired cascaded from one organization to the other. Even though there is still much work to be done, we can surely admit that changes took place.

DRPI Promotes a Bottom-Up Model of Activism of Persons with Disabilities

Sonja, Montenegro
From my point of view, the DRPI project's ultimate worth lies in its bottom-up character. Nobody knows better than people with disabilities what is convenient for them, what should be a priority, what the most troubling barriers are to their inclusion and participation in the community. When we estimate the level of awareness about the right on the autonomy of people with disabilities perceived by the decision-makers, public opinion, and people with disabilities themselves,

including their family members, Montenegro is still far from implementing the "Nothing about us without us" motto. There are exceptions, both within the DPO community and decision-makers, of course. Montenegrin official policy is based on that same principle that gives the chance to international supporters to insist on it when investing their resources in projects with a strong component of empowering people with disabilities and their organizations. To mention the model of good practice, I would stress the high quality of the shadow report presented in Geneva in 2017, which was completely drafted by DPO representatives[8] (cross-disability DPO Youth with Handicap) and which highly influenced the Concluding Observations of the UNCRPD Committee for Montenegro. Our Government's second report is due in 2023 and now is the right time to initiate the second holistic monitoring report (the first one was elaborated in 2013), with at least two components, monitoring individual experiences and media monitoring, while the legislative (systemic) analysis could be done in the working group, which was already the case in the aforementioned analysis carried out in 2016.

Emma, Moldova

A significant period had started when the training was over. We immediately moved on to work and in my situation, I decided to come up with the personal initiative to take under my responsibility the part of the country that had not actually been planned before. That decision came about because it could enlarge the area of monitoring throughout a bigger territory. I realized that it could be much harder to organize, but I dared to take charge, and after we got approval from the coordinator, we began the work. I assume that was partially because of a dose of motivation from the training that inspired me, as a person with disability, to contribute to the creation of change for my fellow citizens with disabilities. During the process of interviewing, I met so many people with disabilities in the northern part of the country, and the interviewing process was so significant for me that I took the decision to continue down that path. I wanted to change our lives. Within a year, I left the capital of the country, moved to another, smaller town, founded an NGO for people with disabilities, and started a new path in my life, where I became a civil rights activist and a human rights promoter.

Here is the point at which to mention the importance of that DRPI training delivered by Sonja Vasic and Rados Keravica, who were also persons with disabilities with whom we could identify, for Moldovan participants. It was a turning point in broadening my horizon in knowledge about disability, human rights, enlarging the circle of people with whom we started to collaborate, and encouraged me to found an NGO for people with disabilities, to work and inspire the others, to listen to the voices "from the field," and to produce the changes. As a result of all the aforementioned points and my direct involvement in disability rights monitoring, one can now see multiple ramps constructed in my town and parking lots for people with

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[8] See more at: http://umhcg.com/wp-content/uploads/2018/Izvjestaj-ENG.pdf

disabilities. Owing to my activism, I had the honor of being invited to present the Moldovan alternative report in Geneva.[9] Thus, contributing to this chapter is an honor and a chance to share with the audience how the involvement in disability rights monitoring and the training in the sphere of disability can change your personal and professional life, your world vision, and participation in the life of the country, changing the lives of people with disabilities for the better, promoting empowerment, equality, and accessible conditions for all.

In summary, I was a participant in the training, who later became a PwD who monitors human rights and who interviewed other people with disabilities throughout the country. This had a considerable impact upon both sides (me as an interviewer and the people I interviewed, creating the opportunity for their voices to be heard) and upon the entire country as well.

Conclusions and Recommendations

Monitoring is a very sophisticated process in implementing the human rights concept in society, aiming to reach equality for all and respect for diversity of any kind. This includes claiming the rights of people with disabilities. DRPI methodology helps to create an independent monitoring system for disability rights, based on three priority areas: (1) individual experiences of persons with disabilities; (2) systemic monitoring that studies legal frameworks, tracks case-law before the courts and statutory human rights bodies, and analyzes general government policies and programs; (3) media monitoring that involves tracking media imagery and coverage of disability. It increases the capacity of DPOs to be able to collect, analyze, and use data to report and advocate, and facilitates cross-disability cooperation and coalitions with other human rights actors.

In the countries of former Yugoslavia and the ex-Soviet zone of influence in Europe, the time for the idea of equal rights for persons with disabilities has come and is strongly supported by the UNCRPD. Persons with disabilities need to learn how to use monitoring skills (collect data, analyze them, and make the best use of the results of monitoring at the right moment, in the right format, and in front of the right actors). DRPI methodology gives clear instructions on how to do so from the very first step to the final success. The methodology is based on gaining knowledge of persons with disabilities, as well as material resources, to become owners of strong arguments and to become prepared to voice their concerns to highly positioned decision makers. Not all people with disabilities or their DPOs would be able to take part in the full process, but all of them can participate partly in the process of monitoring. Knowing that and taking into consideration the fact that the DRPI project has already been implemented in five countries of the mentioned region (Montenegro, Serbia, B&H, Moldova, and North Macedonia), it would be

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[9] UNCRPD Committee's Seventeen session, Geneva. See more at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/SessionDetails1.aspx?SessionID=1141&Lang=en

recommended to continue with the monitoring to start up a new cycle of monitoring, and to compare the findings reported in 2015 with those in 2021/2022. That would reflect the main trends. The pull of people with disabilities who have already been trained should be included in the training of trainers, which could be regionally conceptualized or even delivered in an online format. Dissemination of their knowledge to others should be supported through the nationally financed projects and should include not only DPOs and people with disabilities but also representatives of other human rights organizations, governmental bodies, media representatives, political parties, etc. Elaboration of the holistic monitoring reports should be financed by the governments as part of the preparation of the shadow reporting to the UNCRPD Committee as part of the existing cooperation of the governments and DPOs through the funding streams for DPOs. Clear priority given to this topic must be emphasized in the criteria for project grant awards. Training materials should be slightly adapted to the level of knowledge of the leading DPOs with demonstrated experience in the theoretical and practical dimension of DRPI methodology. Intensive international cooperation should be fostered between academic institutions and DPOs in order to give more scientific credibility, rigor, and visibility to all the aspects of the implementation of the methodology. For the countries of the former Soviet zone of influence, it would be useful to be incorporated in the DRPI project. When I (Sonja) was engaged in the Central Asia Program of Handicap International in Kyrgyzstan and Tajikistan during 2005/2016, I initiated HI Central Asia’s application to the European Instrument for Democracy and Human Rights call for project proposals with the idea of promoting DRPI methodology of monitoring and reporting human rights of people with disabilities in Central Asia, but this application was not listed as the priority of the donor. I think that, on the contrary, it would have been a chance to spread the human rights approach to disability in Central Asia. For many other participants of the project, all the steps undertaken became an equivalent of changing a life, vision, a decrease in negative attitudes, acceptance, liberation, breaking the stereotypes and environmental barriers, acquiring social and legal knowledge and information, and it led to empowerment and an awareness that we have a right to live full and happy lives just like everyone else. In order to spread the positive influence that the DRPI project had on the countries in the accession process to the European Union (EU), it is worth making another effort to present the methodology and the content of DRPI to other regions worldwide and also to support the implementation and scaling of the skills and knowledge gained in European countries that are still not part of the EU.

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Protecting Women and Girls with Disabilities from Violence and Upholding Their Rights: Making It Work Methodology

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Sophie Pecourt and Silvia Quan

Contents

Abstract

The adoption of the Convention on the Rights of Persons with Disabilities (CRPD) marked a milestone in recognizing women and girls with disabilities as full rights holders and in explicitly identifying the multiple discrimination they are subjected to, including gender-based violence. Nevertheless, advancing these rights has posed significant challenges due to the lack of comprehensive disability laws and policies addressing them, or protecting women's rights. The Making It Work (MIW) methodology, applied to the initiative to prevent, eliminate, and respond to violence against women and girls with disabilities, has shown that placing persons with disabilities, particularly women with disabilities, as central actors in the implementation and monitoring of the CRPD, is a successful road for their empowerment and key to upholding their rights. It has also proven to be a useful tool for mainstreaming disability in the broader women's rights movement.

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Introduction

With the adoption of the Convention on the Rights of Persons with Disabilities (CRPD) by the UN General Assembly on December 13, 2006, the participation of persons with disabilities became an essential element in any decision-making process. During the ad hoc Committee sessions (2002–2006) that developed the text of this new human rights treaty, the voices of civil society were strong and unprecedented (UN Special Rapporteur on the Rights of Persons with Disabilities, 2016), and it was not any kind of civil society: It was the voices of persons with disabilities who had long been silenced and taken over by others, mainly service providers and so-called "disability professionals." It was the motto "Nothing about us, without us!" put into practice at its highest standards, and persons with disabilities worldwide celebrate the long-cherished result, a human rights treaty which recognizes the dignity and fundamental rights and freedoms of all persons with disabilities.

The CRPD is not only unprecedented because of how it was drafted and the unique way in which the knowledge and experience of its rights holders were tightly knit into it, but also the CRPD is broad and comprehensive, and by being so, it has captured intersectionality in its essence. Its Article 6, women with disabilities, which recognizes that women and girls with disabilities are subjected to multiple forms of discrimination, is just one example of how comprehensive this fundamental treaty is, and how powerful its use as an advocacy tool can result. Article 6 and other provisions which are fundamental to basic concerns relating to gender-based violence, such as Article 16 – freedom from exploitation, violence, and abuse, Article 17 – personal integrity, Article 23 – respect for home and family, and Article 25 – the right to health, were also drafted with the unprecedented voices of women with disabilities being heard during the discussions of the Ad Hoc Committee, and today, over 14 years after its adoption and 12 years since its entry into force, women with disabilities who played a key role in the early turn of the millennium have stayed active in its enforcement.

The CRPD Committee has also played a fundamental role with its monitoring tasks. With its ongoing work developing jurisprudence, it has adopted seven general comments so far, its general comment no. 3, adopted during its 16th session in September 2016, being on women and girls with disabilities (Committee on the Rights of Persons with Disabilities, 2016). GC3 stresses the importance of intersectionality when dealing with major concerns of women and girls with disabilities; in particular, it points out how some of the most perverse and widespread forms of violence against women and girls with disabilities, such as forced sterilization, cannot be fully understood unless using an intersectional lens for its analysis.

The restriction to the enjoyment of full legal capacity, the absence of free and informed consent that leads to forced treatment and violation of sexual and reproductive rights, the persistence of institutionalization, and prevailing stigma and misinformation are only some of the rights of women and girls with disabilities which are continuously and systematically violated. The fundamental nature of human rights as being universal, interrelated, and indivisible means that protecting women and girls with disabilities against violence, exploitation, and abuse can only be achieved if full legal capacity is recognized, nondiscrimination becomes a cornerstone in the development of policies and legislation in the prevention, elimination, and response to gender-based violence, including access to justice with a gender and disability perspective, and gender-sensitive de-institutionalization, and independent living schemes are put into place, including personal assistants to facilitate access to sexual and reproductive health and rights, and access to inclusive education and social protection with gender and disability perspective.

General comment no. 7 on the participation of persons with disabilities and their representative organizations in the implementation and monitoring of CRPD, adopted by the CRPD Committee (Committee on the Rights of Persons with Disabilities, 2018), has also acknowledged the importance of women and girls with disabilities constituting their own organizations, and in particular, to be included in consultations referring to issues that will affect them more disproportionately. In addition, women and girls with disabilities should also be able to fully participate in monitoring mechanisms of human rights, particularly in independent monitoring mechanisms for the CRPD. Special attention should be paid to the independent monitoring authorities appointed in conformity with Article 16, para 3, on the right to freedom from exploitation, violence, and abuse.

The former UN Special Rapporteur on the Rights of Persons with Disabilities, Ms. Catalina Devandas Aguilar, also a woman with disability herself and an outstanding actor in the development of interpretation standards for the rights of persons with disabilities, in her 2017 thematic report on sexual and reproductive health and rights of young women and girls with disabilities (Special Rapporteur on the Rights of Persons with Disabilities, 2017), has pointed out how women and girls with disabilities have been subjected to widespread gender-based violence, harmful and forced practices, prevailing stigma and stereotypes due to gender and disability, and multiple and intersectional discrimination that limits or fully restricts their access to sexual and reproductive health and rights, many of these related to the lack of autonomy and disempowerment, arbitrary deprivation of liberty, and nonaccessible facilities and transportation, to the lack of education, information, and communication, and the lack of policies recognizing the full legal capacity for all persons with disabilities. The risks of gender-based violence against women and girls with disabilities significantly increase in contexts of irregular migration, in conflict settings and humanitarian situations caused by natural disasters.

These major concerns and the subsequent recommendations that have been issued by these two expert bodies, referring to women and girls with disabilities, have been echoed by other international experts and human rights organs, including the Office of the High Commissioner for Human Rights (OHCHR), the Special Rapporteur on violence against women, its causes and consequences, the Special Rapporteur on the right to physical and mental health, and the Committee on the Elimination of all Forms of Discrimination Against Women (CEDAW Committee), among others. There is an increasing need to monitor the compliance of human rights of women and girls with disabilities, and to make them enforceable; in particular, these needs are accompanied with growing evidence that follow-up and monitoring policies and legislation to prevent, eliminate, and respond to the gender and disability-based violence should be designed and conducted by rights holders, that is, by women and girls with disabilities and their representative organizations.

The positive outcomes of the participation of persons with disabilities, and their representative organizations in the ad hoc Committee and subsequent adoption of the CRPD, encouraged the participation of a strong movement in the process to assess the disability-lacking millennium development goals (MDGs), and to draft and adopt, in mid-2015, the 2030 sustainable development agenda and its sustainable development goals (SDGs). The success of this lobbying was demonstrated with the 17 goals being fully inclusive, and with an unprecedented number of explicit references to persons with disabilities in several of the adopted indicators.

Many efforts have been set forth in order to achieve effective monitoring of CRPD compliance, and as there has been a growing tendency to link human rights provisions to the UN sustainable development goals (SDGs), more initiatives are being implemented by diverse stakeholders, from different approaches and perspectives, and using diverse methodologies. Monitoring human rights and building indicators for this purpose has been challenging, and the lack of data on persons with disabilities has been a major barrier. In order to tackle this, the OHCHR has established some standards, and in late 2020, as part of the EU-funded project "Bridging the Gap I" (see https://bridgingthegap-project.eu/crpd-indicators/), it launched a tool kit, including a set of CRPD-SDGs human rights indicators, that had been piloted in five countries of the world, one country per UN region. Other relevant monitoring initiatives include the ten gold indicators developed by the Danish Institute for Human Rights (see https://www.humanrights.dk/news/gold-indicators-measuring-10-key-thematic-areas-improve-situation-persons-disabilities), which were closely selected in consultation with persons with disabilities and their representative organizations, or the set of indicators proposed by Disability Rights Promotion International resulting from the monitoring projects led by persons with disabilities (Rioux, 2017).

This chapter's aim is to show how a methodology developed to collect and replicate good practices in CRPD implementation has been used by persons with disabilities, and more recently, by women with disabilities, to monitor progress. It has also served to scale up local efforts to national, regional, and international levels, and to mainstream women's organizations. By learning with successful examples of how persons with disabilities have tackled violence against women with disabilities by involving men through education, or have shown their governments how to implement supported decision-making in access to justice, others have found practical guidelines on how to progress within their own context.

The MIW Methodology

In 2008, the international development and disability organization Humanity&Inclusion (HI), former Handicap International, developed the “making it work” methodology (MIW) consisting of identifying, documenting, and analyzing good practices that have proven to be successful models in CRPD implementation, to serve as a guiding tool for organizations of persons with disabilities (OPDs) in other contexts or countries to replicate, or even to scale up. MIW offers persons with disabilities and OPDs a more practical methodology to monitor CRPD progress, an added value to more academic approaches such as monitoring through human rights indicators. Through the identification, documenting and analysis of practices, and the possibility of replicating them, persons with disabilities feel empowered by demonstrated evidence that change is possible through their participation.

During 7 years, HI in collaboration with partners worldwide had been implementing over 60 projects in 25 countries using the MIW methodology in almost any topic contained in CRPD, including legal capacity and access to health, education, employment, water, and sanitation. The MIW methodology comprised several criteria, but the fundamental elements include the following: Persons with disabilities are the key actors of the experience or good practice in implementation of one or several articles of the CRPD; the practice has resulted in significant change for persons with disabilities, change being defined in the adoption of laws or policies, discriminatory customs or practices put to an end, increase in budget allocation that improves inclusion of persons with disabilities, and/or increased accountability.

While CRPD awareness at the international level is advancing quickly with more jurisprudence and legal changes taking place, women with disabilities still face enormous gaps and inequalities, given the persistence of multiple and intersecting forms of discrimination and the lack of gender perspective in CRPD implementation and enforcement. With an increasing number of organizations of persons with disabilities (OPDs) using MIW methodology, in 2014 HI decides to launch its gender and disability MIW initiative to prevent, eliminate, and respond to violence, abuse, and exploitation of women and girls with disabilities that lead to their empowerment, reflect their diverse experiences and preferences, and promote their equity.

The gender and disability MIW initiative was first launched with the establishment of a technical advisory committee (TAC), comprised of 17 local and global independent experts on gender and disability, of whom six members are women, four are women with disabilities, four are based in the USA, one is from Europe, one is from Latin America, and one is from Africa; this composition would later be modified as the TAC expanded its membership. The TAC would work jointly with the HI project coordinator and management. To select the TAC members, the MIW coordinating team considered the lived experiences at the intersection of gender and disabilities, knowledge and experience at the international level, and diverse backgrounds such as academia, international development and cooperation, global humanitarian action, and human rights.

The main responsibilities of the TAC are the following: to review the project design and provide recommendations to the MIW coordinating team; to advise on gender and disabilities issues; to help define the focus of the good practice collection, including good practice criteria and scope of good practices; to review and select good practices; to promote the value of the project in diverse settings and within diverse networks; and to assist the MIW coordinating team in the dissemination and application of the good practice findings to key international level actors and within key international events. The TAC aimed to build a bridge so that women with disabilities from local grassroots organizations could reach out to mainstream local, national, and international women's organizations and to the broader international organizations of persons with disabilities, State actors, and multilateral organisms, so their voices and concerns can be heard.

In order to do so, the TAC has been drawing recommendations from good practices. In the 2015 Report, for instance, the TAC made recommendations to governance and justice reform programs and human rights institutions in order to enforce the realization of articles 4 (General obligations) and 12 (Equal recognition before the law) of the CRPD. Denouncing the insufficient links between disability-focused civil society organizations and States and/or multilateral actors, the MIW TAC called States, disabled people's organizations, mainstream civil society organizations, and UN agencies to give greater room to the voices of women and girls with disabilities in global and local conversations on gender equity. According to article 4.3 of the CRPD, experts were calling for systematic consultation between State actors and gender-focused civil society organizations of women with and without disabilities and their organizations are needed during policy-making and tools development, such as action plans.

Focusing on the topic of empowerment (individual as well as organizational empowerment), the MIW Technical Advisory Committee highlighted the need to increase and upscale capacity development programming for disabled people's organizations, States, UN agencies, and service providers engaged in the protection and redress of gender-based violence. TAC called on States to allocate sufficient resources on capacity development in these areas, including through funds dedicated to international cooperation and emergency situations, in realization of articles 11 and 32 of CRPD.

In 2014, the gender and disability MIW TAC discussed how to strengthen the leadership of women with disabilities and their representative organizations, who were struggling to visibilize the enormous gaps that the majority of persons with disabilities, almost 60% according to the World Health Organization and the World Bank (2011), are facing due to noncompliance with the CRPD provisions referring to preventing, eliminating, and responding to gender and disability-based violence. They aimed to demonstrate that placing women and girls with disabilities at the center of these advocacy efforts could be successful and, even better, be replicated by peers worldwide.

The first international call for good practices defined the following priority areas:

(i) Issues of access for women and girls with disabilities in order to prevent and eliminate violence, exploitation, and abuse, which included the following: access to and education in health, including sexual and reproductive health, access to education and employment, access to justice, and access to support services and reasonable accommodations (CRPD articles 2, 5, 13, 16, 24, 25, and 27)
(ii) Issues of rights protection of women and girls with disabilities in order to prevent violence, abuse, and exploitation, which included the following: autonomy and right to live in the community, forced medical treatment and forced sterilization and informed consent, and legal capacity (CRPD articles 12, 15, 16, 17, and 19)
(iii) Tools and strategies that support the prevention and elimination of violence, abuse, and exploitation of women and girls with disabilities, which included: data collection on violence, abuse and exploitation disaggregated by gender, age and disability, and other identities, identification of girls with disabilities in relation to education, access to information, awareness raising and public education on the elimination of gender and disability stereotypes, and practices that address violence, abuse, and exploitation of women and girls with disabilities in situations of risk, humanitarian emergencies, and natural disasters (CRPD articles 8, 11, 16, 21, 24, 31, 32)

The TAC also defined the following criteria to select the good practices: (i) practices that show evidence of having made a positive change, wherein change could include policies/legislation, practices, attitudes, changes in the community, in budget allocation, and increasing visibility and/or commitment in mainstream organizations and/or governments; (ii) practices that promote diversity of women and girls with disabilities; (iii) practices that show demonstrated leadership of women and girls with disabilities in the design, implementation, monitoring, and evaluation of the practice; (iv) practices that show evidence toward achieving gender equity; and (v) practices that promote collaboration with women and girls with disabilities.

The MIW methodology was built by appropriating the motto “nothing about us without us.” In the wake of CRPD elaboration where persons with disabilities and their organizations played an unprecedented role, persons with disabilities are put at the center. The MIW methodology, and its subsequent use in particular by the Making It Work Gender and Disability initiative, was innovative in many ways:

- First, MIW has been reaffirming that women with disabilities are not only “subjects of law” but rather also informed and engaged rights holders. This has been done through placing the leadership of women with disabilities as a mandatory criterion for being a good practice.
- Second, selecting good practices implemented at community and local level, MIW has been bringing them as evidences to different human rights bodies and major regional and international human rights fora, using a bottom-up approach that was not so frequent years before the localization was put at the center of the conversation.

- Third, the MIW gender and disability initiative has also considered that preventing, eliminating, and responding to gender and disability-based violence against women and girls with disabilities crosses over to compliance with the Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW) and the sustainable development goals (SDGs). This has been a crucial step to engage women with disabilities outside the disability rights movement and monitoring processes.

Focus on the Making It Work Gender and Disability Project

Since its formal launch in 2014, the Making It Work gender and disability initiative has been conducting three rounds of good practices selection.

The first global call for good practices resulted in the selection and further documentation of 11 good practices in ten countries (Fiji, Colombia, Costa Rica, Guatemala, Mexico, Uruguay, Israel, Kenya, Canada, and Burundi), presented in the 2015 Making it Work Initiative Report entitled, "Gender and Disability Inclusion: Advancing Equity for Women and Girls with Disabilities" (Handicap International, 2015a). Those practices, mostly implemented by local and grassroots organizations, were operating in three areas: legal advocacy and policy change; awareness raising; and empowerment.

As stated in the key findings from those ten practices, women with disabilities across the globe who report cases of violence and abuse to the police face multiple barriers in accessing justice, seeking violence prevention and response services, and exercising their legal capacity. The different barriers faced are illustrated by the practices, of which the good practice titled "InFocus: Bringing people with disabilities into the picture—A National Pan-Canadian Community Leadership Initiative implemented" is by DisAbled Women's Network/Réseau d'action des femmes handicapées (DAWN—RAFH), Montreal, Canada. DAWN developed an assessment tool, the "National Accessibility and Accommodation Survey" (NAAS), and undertook an accessibility assessment of domestic and gender-based violence shelters and programs. From there, the Project raised awareness on experiences of women with disabilities with regard to violence throughout Canada, focusing on local OPDs and relevant context in each community. Some workshops focused on disability sensitivity training for healthcare providers, violence prevention workers, teachers, police, and other frontline workers. Information sessions were held to understand challenges and barriers, and how to practically address inclusion in the workplace. The second group of workshops raised awareness among women and girls with disabilities on risk factors for gender-based and sexual violence, explored proactive steps women could take in such situations, and enhanced the understanding of women with disabilities with respect to addressing violence and obtaining services.

Another good practice implemented by Disability Rights International Guatemala and titled "Protecting the lives and integrity of women with disabilities detained at the National Mental Health Hospital, Guatemala, through the Inter- American Human Rights System" focused on the topic of legal protection of women with psychosocial disabilities against violence, abuse, and exploitation. MIW documented the process undertaken by DRI and many stakeholders (families, patients, staff, local advocates, and mental health experts) to thoroughly document human rights abuses occurring in the Federico Mora hospital in Guatemala and ultimately file a precautionary measure petition to the Inter-American Commission on Human Rights (IACHR) with the aim of protecting the physical and sexual integrity of those housed within the hospital. The petition outlined abuses ranging from arbitrary detention; lack of appropriate supervision; routine physical, sexual abuse and the use of forced contraception; dangerous use of isolation rooms; inadequate and dangerous medical treatment; inhuman and degrading conditions; and a general lack of food and water. Women with psychosocial disabilities were found to be at very high risk of sexual abuse and exploitation which made this hospital especially dangerous for women. This is an aspect of violence against women that is rarely investigated, and it has helped raise the profile of the vulnerability of women and girls with disabilities in institutions around the region. As a consequence, the Government of Guatemala has been pursuing efforts to implement the precautionary measures as prescribed by the IACHR. It also engaged with Pan-American Health Organization (PAHO) to draft a new mental health law.

The good practice titled “Mainstreaming disability in the governmental programs addressing violence against women in Uruguay,” implemented by the Ministry for Social Development – Gender Unit of the Disability Program, helped illustrate how to conduct disability mainstreaming within governmental programs, with a focus on women with disabilities and access to sexual and reproductive health (related to CRPD Articles 6, 16, and 25). Through the capacity-building “Sweeping Barriers” program, both the civil society and staff from the health sector were targeted. The seminars for OPDs and civil society organizations included the rights of persons with disabilities emphasizing the sexual and reproductive rights and the right to have a life free of gender-based violence. The civil society organizations were consulted to promote the direct participation of women and girls with disabilities. The seminars aimed at health professionals and Ministry staff included topics such as the social model of disability, the legal framework protecting the rights of persons with disabilities, and violence against persons with disabilities. A strategic alliance with the Health Services’ State Management was developed. Among the key successes of this practice, one can highlight a guide has been published on sexual and reproductive rights of persons with disabilities, with a gender focus. It is compulsory reading for university students pursuing careers in medicine, nursing, and gynecology. Once data on gender-based violence began to be collected, women and girls with disabilities who were legally incapacitated and also were victims of violence started being assisted with no need for their legal representative to speak for them. Although this practice did not challenge a denial of legal capacity, this change in practice has been an advancement in the protection against gender-based violence in Uruguay and the enforcement of Articles 6 (Women with disabilities), 16 (Freedom from exploitation, violence, and abuse), and 25 (Health).

The good practice titled “Advocacy for legal education in Colombia,” implemented by the coalition made of Profamilia, Fundamental Colombia, ASDOWN, and University Los Andes' Action Program for Equality and Social Inclusion (PAIIS), focused on protecting women and girls with disabilities from forced sterilization. The report explains that when this practice began the legal representatives or guardians had the right to decide to sterilize the person whom they represented. Sterilization was often performed as a form of "protecting" the person with disabilities against sexual abuse, or this was the argument often used for this type of intervention. Once Colombia ratified the CRPD and became a State Party, the coalition started questioning the legality of forced sterilization. Then it decided to legally challenge forced sterilization, using CRPD article 12 and 17 as a legal framework and arguments. Among a series of action, the coalition led by Profamilia designed an advocacy strategy which included the following: awareness-raising activities aimed at health professionals and practitioners, judges and judicial staff, families of persons with disabilities, and persons with disabilities themselves; a legal strategy aimed at challenging a denial of legal capacity and forced sterilization based on this criteria; promoting the autonomy and respect of the will and preferences of persons with disabilities; and promoting choices in sexual and reproductive health services. The legal strategy included discussions with judges who had declared persons with disabilities as legally incapable, informing them about the CRPD, particularly the scope of article 12 (Equal recognition before the law), and article 17 (Protecting the integrity of the person). The outcome of these actions, in addition to legally challenging all legal provisions allowing for the restriction of legal capacity for persons with disabilities, was a decision of the court to allow forced sterilization only in cases when this medical intervention had been authorized by a judge's order.

The MIW Report gained significant attention as it was giving an unprecedented visibility to women with disabilities and their organizations actively engaging in inclusion, gender equality, and the fight against GBV. At a time where intersectionality was not commonly referred to in the global conversation, in particular when articulating discrimination based on disability as one of the intersecting factors, the 2015 MIW Report was an eye-opener to many; it showed that women leaders with disabilities were actually contributing to an increased enjoyment of their rights as enshrined in the CRPD. The Report also highlighted key recommendations drawn by good practice holders and TAC members all together, focusing on States obligations with regard to several articles of the CRPD as well as commitments expected by nonstate actors, NGOs, etc. In line with the MIW methodology aimed at bringing lasting change through documented successful good practices, the report helped showcasing women-led practical initiatives to enhance the fulfillment of States' obligations and further commitment of civil society actors.

In 2015 and 2016, a series of events and publications subsequent to the MIW report's publication brought together women leaders with disabilities to effectively advocate for change using good practices as evidence. Those were addressing rights violations and human rights monitoring using legal instruments such as CEDAW, CRPD, and the SDGs.

First, the HI-Making It Work initiative organized a session at the Commission on the Status of Women (CSW) at the United Nations in March 2015. This session brought together women leaders implementers of good practices from Kenya and Mexico and Guatemala (namely, Milanoi Koiyiet, on behalf of the Kenyan Association for the Intellectually Handicap (KAIH) and the Kenyan Coalition on Violence Against Women (COVAW); Priscila Rodriguez, on behalf of Disability Rights International (DRI); and Natalia Santos ESTRADA, representing the Collectivo Chucan, an organization of self-advocates for the rights of women and men with psychosocial disabilities from Mexico City) as well as global advocates such as Stephanie Ortoleva, Director of Women Enabled International and member of the TAC, Ms. Catalina Devandas, UN Special Rapporteur on the Rights of Persons with Disabilities (via video), and Jeong Shim Lee, of UN Women. It helped to highlight some practical successes in an effort to fight gender-based violence targeting women with disabilities, as well as advocating and inspiring more action on ending violence.

Second, 2015 was the year of the Beijing+20 review of the Beijing Declaration and Platform for Action. At that occasion, HI-Making It Work together with Women Enabled International and Syracuse University College of Law (Disability Law and Policy Program) published a review of 15 Country Reports to CSW, titled “Where are the girls and women with disabilities: an analysis of the country reports submitted to the Commission on the Status of Women 59” (HI, 2015b). The document recalled the disability-inclusive nature of the Beijing Declaration and Platform for Action, as well as the recommendations from the 2000 Special Session of the United Nations General Assembly, reviewing the progress of the outcomes of the Fourth World Conference on Women, stating that Governments should: “Adopt and promote a holistic approach to respond to all forms of violence and abuse against girls and women of all ages, including girls and women with disabilities, as well as vulnerable and marginalized women and girls in order to address their diverse needs, including education, provision of appropriate health care and services and basic social services (General Assembly 2000).” After a cross-comparison of the recommendations of the BPfA and the provisions of the CRPD, the analysis of the Country Reports from Colombia, Costa Rica, Czech Republic, Fiji, India, Ireland, Israel, Japan, Kenya, Mexico, Russian Federation, Rwanda, South Africa, United Kingdom, and Uzbekistan concludes that “the vast majority of country reports do not even mention women and girls with disabilities at all or what the State has done under each of the critical areas of the Beijing Platform for Action with respect to girls and women with disabilities. And, only two country reports involved organizations of people with disabilities (OPDs) to some extent in the preparation of their reports.” Putting the spotlight on what they call a “nearly complete failure of this sample of countries to mention women and girls with disabilities” in country reports yet focusing on women’s rights, the Making It Work Initiative and its partners call for “Women with disabilities [to be] included in all discussions with governments, women’s rights organizations.”

That same year, the MIW initiative raised the voice of women and girls with disabilities at the Civil Society Forum during the Third International Conference on Financing for Development, Addis Ababa, July 2015. It was represented by Yetnebersh Nigussie, Technical Advisory Committee member, and Fatma Wangare from Kenya Association for the Intellectually Handicapped (KAIH). A statement was published, titled "Including women and girls with disabilities in Financing For Development –Towards an all-inclusive and effective Sustainable Development Goals" (HI-MIW, 2015), signed by twenty women-led organizations, academics, and the Technical Advisory Committee of MIW. Although the Action Agenda adopted did not eventually reflect on the gaps experienced by women and girls with disabilities, it was the first time that women with disabilities were represented in such a forum.

In 2016, a delegation of Women with disabilities among the good practice holders of the Making It Work Initiative joined the 2016 AWID (Association for Women's Rights in Development) Forum. Natalia Santos Estrada from Colectivo Chucan, Mexico, Fatma Wangare from Kenya Association for the Intellectually Handicapped, and Priscila Rodriguez from Disability Rights International were actors of a significant change happening in this major event. They led a panel titled "Strengthening our Collective Power: Engaging women and girls with disabilities to end violence against all women and girls." The number of women with disabilities attending was increased, as a result of a deliberate strategy for wider inclusion and diversity (see https://www.awid.org/sites/default/files/atoms/files/summary_report_2016.pdf). Experiences and perspectives of women with disabilities in their diversity as well as key messages to feminist organizations, donors, and policy makers were shared. Women with disabilities realized that intersectionality between gender and disability was a start meant to embrace more diversity, in particular through migrant women and trans women.

Last, the good practice holders had the opportunity to raise their issues and share their experiences within the international disability rights community at the Conference of States Parties (COSP) to the CRPD at the UN in June 2015. A dedicated side event was held to support the local practices and to call attention to the inadequacy of responses to violence against women and girls with disabilities, by highlighting the issues and promoting existing solutions in need of upscaling and replication. Global activists members of the Technical Advisory Committee, as well as the local grassroots experts from the good practices, presented their concerns, the documented successes in addressing violence, and launched a call for action to States Parties to the CRPD, UN agencies, Organizations of Persons with Disabilities, and mainstream development and gender organizations.

After a 2-year period of success where Making It Work good practice holders and TAC members gave an unprecedented visibility to the experiences of women with disabilities and their fight for human rights, the Making It Work Initiative has been enlarging its body of evidence through two additional call for good practices, focusing on countries from the African continent. To reflect on its positioning at the intersection of gender and disability, the TAC was open to a couple of new members from the feminist movements as well as a representative from the African Disability Forum. With similar criteria and the same robust methodology, 17 good practices were selected and further documented in 2017 and 2019 by the TAC members. Addressing violence and discrimination against women and girls with disabilities, good practices have been successfully implemented in nine countries

(Burundi (1); Cameroon (1); Kenya (6); Malawi (2); Mali (1); Nigeria (1); Rwanda (2); and Uganda (3)).

To illustrate the increased use of other instruments such as the Convention for the Elimination of all forms of Discrimination against Women (CEDAW), 2018 MIW report highlights both CRPD and CEDAW Articles at stake. As for CRPD, good practices in general provide practical actions to enhance the enforcement of articles 6, 8, 9, 11, 12, 13, 15, 16, 17, 18, 21, 23, 25, 26, 28, 29, and 30 (CRPD Art. 6 Women with disabilities; 8 Awareness-raising; 9 Accessibility; 11 Situations of risk and humanitarian emergencies; 12 Equal recognition before the law; 13 Access to justice; 15 Freedom of torture or cruel, inhuman or degrading treatment, or punishment; 16 Freedom from exploitation, violence, and abuse; 17 Protecting the integrity of the person; 18 Liberty of movement and nationality; 21 Freedom of expression and opinion, and access to information; 23 Respect for home and the family; 25 Health; 26 Habilitation and rehabilitation; 28 Adequate standard of living and social protection; 29 Participation in political and public life; Article 30 Participation in cultural life, recreation, leisure, and sport). CEDAW Articles relevant to the good practices are Articles 5, 7, 9, 12, 14, 15, and 16 related to sex roles and stereotyping, political and public life, nationality, healthcare and family planning, rural women, equality before the law, and marriage and the law.

Without giving an exhaustive list of good practices, one can highlight here some very emblematic ones to show how practical and diverse the practices are, uplifting the rights of women with disabilities in all their diversities. That is the case of the work of the Inclusive Friends Association (IFA) in Nigeria, located in the conflict-prone Plateau State, aimed at “restoring the dignity of women and girls with disabilities.” GBV legal framework is certainly insufficient in Nigeria, and the UN Security Council resolution 1325 on “Women Peace and Security” addressing GBV is not inclusive of women and girls with disabilities. In that context, IFA conducted a study which was published with the title “What Violence Means to Us: Women with Disabilities Speak.” Mainly conducted by women with disabilities, and focused on women with physical and sensory disabilities over the age of 17 years, in times of relative peace as well as during conflict, the study was widely disseminated and served its advocacy purpose, bringing evidence to leaders, media, and civil society. Women with disabilities gained representation in the Disability Rights Commission of Plateau State, and IFA strengthened partnerships to increase survivors’ access to services, among other results.

In Kenya, the good practice of Women Challenged to Challenge (WCC) titled “Protecting urban refugee women and girls with disabilities from abuse and discrimination” targeted women facing intersectional discrimination linked with their gender, their disability status, and their refugee situation. WCC has been working on increasing accessibility of and access to services for women with disabilities being urban refugees. Conducting training programs for urban refugees with disabilities in Nairobi, focusing on economic empowerment, sexual and reproductive health, and legal rights, WCC helped raise the voice of those women in major international events such as the Conference of States Parties of the CRPD (COSP) in 2016.

The remarkable work of the Visual Hearing Impairment Membership Association (VIHEMA) in Malawi is described in the good practice titled "Advancing the access of deafblind women and girls to Sexual and Reproductive Health." Willing to tackle the issue of forced sterilization, a procedure recommended by health practitioners to prevent unwanted pregnancy resulting from rape, VIHEMA has been raising awareness on the issues to all parties involved: families, caretakers, health practitioners, and leaders. Sensitization sessions were conducted by deafblind women from the community, helping to change the mindset of the community about the women and girls living with deafblindness. Through a range of activities also targeting economic empowerment and family planning, VIHEMA's good practice proved to be empowering at an individual level, as well as at community level, by overcoming deafblind women's isolation and denial of rights over their bodies.

Many good practices have been targeting access to justice for women and girl survivors of violence. Disabled Women in Africa (DIWA) Malawi has been working with traditional leaders to ensure that traditional bylaws are not in contradiction with the rights of the women survivors. They have been tackling the issue of cases dropped off by police through direct cases follow-up, making this possible through helping women with disabilities creating their own self-help groups. United Disabled Persons of Kenya (UDPK) has been holding dialogue forums with health and judicial professionals to enhance access to justice for women survivors. In Northern Uganda, the National Union of Women with Disabilities (NUWODU) has been establishing a community network of paralegals to develop access to justice. Again in Kenya, the Coalition on Violence Against Women (COVAW) has been long involved in access to justice for women with disabilities in partnership with the Kenya Association for the Intellectually Handicapped (KAIH). Their good practice, titled "Enhancing access to justice for Gender-Based Violence survivors with intellectual challenges through integrated legal and psychosocial support service provision," describes how they have been using their expertise and evidence gained through following cases of women and girls with disabilities to work with the justice system. A major success was obtained through their participation in the review of judicial procedural obligations in Kenya. COVAW and KAIH submitted proposals regarding reasonable accommodations for persons with intellectual disabilities in the bench book for criminal proceedings, drafted by the Judicial Committee. COVAW notably focused on the necessity of providing sign language interpreters, physical guide assistance, and intermediaries if required. Those propositions were integrated into the final draft, leading to a major increase of accessibility of justice for women and girls with intellectual disabilities, and to some extent to all women and girls.

Intersectionality is progressively recognized as an effective approach to addressing women's rights. In Kenya, MIW documented a good practice by the Kenya Female Advisory Organization (KEFEADO), an intersectional feminist organization active in Western Kenya and at the national level. Titled "Using sports and art to discuss gender-based violence with children and young people with disabilities," their practice shows how feminist organizations can practically address the rights of those with disabilities, and include their perspectives in their advocacy work, through partnerships with women-led OPDs.

Using the good practices as evidence and resources, the Making It Work initiative has been continuously contributing to enforcing the implementation of the CRPD and CEDAW in line with the SDGs, with a clear focus on discrimination and violence against women and girls with disabilities. The good practices have given substance to five submissions to Special Rapporteurs and are cited in major international resources.

Evidence from good practices was shared with the Secretary General for his Report titled "Situation of women and girls with disabilities," published in July 2017 (A/72/227). The good practice implemented by COVAW and KAIH in Kenya, documented under the title "Breaking the silence around sexual- and gender-based violence against boys and girls, women and men with intellectual disabilities in Kenya," was a resource used for the UNFPA Global Study on Young persons with disabilities (UNFPA, 2018).

In 2019, the Making It Work gender and disability initiative used documented practices and further contributions from Good Practice Holders to make submissions to several Special Reports:

- Report of the Special Rapporteur on Violence against women, its causes and consequences, at the occasion of the 25th anniversary of the mandate (A/HRC/41/42, June 2019): MIW submission has recalled the need for intersectional laws and policies, as well as sharing examples of harmful practices rooted in cultural and social norms targeting particularly women and girls with disabilities. This submission highlighted findings from the practice of VIHEMA Deafblind Malawi on the issue of forced sterilization and "unintended violence" faced by women and girls with disabilities. It elaborated on the lack of agency and ownership that women and girls have over their bodies in certain communities (HI-MIW, 2019a).
- Report of the Special Rapporteur on the rights of persons with disabilities, on the Rights of Older Persons with Disabilities (A/74/186, July 2019): MIW submission (HI-MIW, 2019b) was elaborated together with three good practice holders, namely, Cameroon Baptist Convention Health Services for Persons with Disabilities (CBCHS), Lira District Disabled Women Association, Uganda, and Women Challenged to Challenge, Kenya. Building on their practices and their extensive knowledge of their context, it elaborated on the legislative and policy frameworks and access to healthcare for older persons with disabilities.
- Report of the Special Rapporteur on violence against women, its causes and consequences on a human rights-based approach to mistreatment and violence against women in reproductive health services with a focus on childbirth and obstetric violence (A/74/137, July 2019): MIW submission combined facts from the documentation of good practices with direct contributions from four good practice holders, namely, Mubende Disabled Women's Association (MUDIWA), Uganda, Organisation pour un Développement Intégré au Sahel (ODI Sahel), Mali, United Disabled Persons of Kenya (UDPK), Kenya, and Union des Personnes Handicapées du Burundi (UPHB), Burundi (HI-MIW, 2019c). Documenting mistreatment of women and girls with disabilities during SRH care, childbirth, and prenatal and postnatal care, the submission shared stories

> illustrating how women with disabilities experience such mistreatments amounting to violence against women and other human rights violations such as the right to be free from torture or cruel, inhuman, or degrading treatment or punishment (CRPD Article 15, Universal Declaration of Human Rights Article 5). Recalling the CRPD Committee, General Comment No. 3 that focuses on CRPD Article 6 (Women with disabilities) and its links with Article 16 (Freedom from exploitation, violence, and abuse), Articles 23 (Respect for home and the family), and Article 25 (Health), the submission elaborated on forced abortion, forced contraception, and forced sterilization as well as the failure in ensuring that informed consent is sought, whether due to health professionals lacking the knowledge of needed processes, or them denying the right to informed consent to women with disabilities.

In 2019, two Making It Work good practice holders, namely, Disabled Women in Africa (DIWA) and Lira District Disabled Women Association (LIDDWA), Uganda, submitted their contributions to the Special Rapporteur on the Rights of Persons with disabilities on good practices to ensure effective access to justice for persons with disabilities. Both organizations have been building their contributions from their expertise and successful practices. DIWA Malawi, highlighting good practices in place such as free legal services provided by the Ministry of Gender in Malawi, elaborated on recent positive developments such as age- and gender-appropriate accommodations being put in place following their cooperation with the Chief Justice (DIWA, 2019). LIDDWA provided inputs on good practices in place nationally, such as Sign Language being one of Uganda's official language.

Conclusion

Since many years now, MIW country partners have been more equipped with confidence and practice to submit to treaty bodies for the monitoring of CEDAW, CRPD, and other reporting mechanisms such as the Universal Periodic Review (DIWA, 2020; UNABU, 2017). Being localized and providing inspiring and practical examples of successful practices, those contributions aim at supporting Governments and other stakeholders for a better gender perspective in the implementation of CRPD (see https://disabilityrightsfund.org/crpd-committee-publicizes-list-of-issues-for-malawi/), and more systematic inclusion of women with disabilities in CEDAW monitoring and women's rights-related efforts. Having gained their seat at the table, women with disabilities had to be present during the last major advocacy event that is the 25th anniversary of the Beijing Declaration and Platform for Action (Beijing+25).

As discussed earlier in this chapter, the 2015 Beijing+20 review had been showing a poor level of inclusion of women with disabilities. A study by Handicap International-Making It Work together with Women Enabled International and Syracuse University College of Law (Disability Law and Policy Program) published a review of 15 Country Reports to CSW. They concluded to a "nearly complete failure of this sample of countries to mention women and girls with disabilities.” The Civil Society review in 2015 was also not giving sufficient and meaningful space for women with disabilities. Five years later, the Civil Society review process in Africa demonstrated that women with disabilities could no longer be overlooked. Total 15 women-led organizations shared their updates on selected critical areas, compiled in a report titled “Perspectives of Women with Disabilities on the Implementation of the Beijing Platform for Action + 25: Africa Region – Contribution to the Africa Regional Parallel Report 2019″ compiled by MIW and IDA (Oct 2019).” As a result, the Beijing+25 Civil Society Parallel Report for Africa (FEMNET, 2019) includes women with disabilities and the intersectional approach like never before.

Making It Work has been providing a new way to uphold the implementation of human rights treaties and other international human rights frameworks; this in parallel with more traditional but necessary human rights monitoring based on national and civil society reports documenting human rights violations. The comprehensive documentation of successfully implemented good practices led by the rights holders themselves allowed the initiative to bring the perspectives and realities of women with disabilities at a higher level. The inherent credibility of women leaders advocating for their rights has been opening doors and progressively breaking barriers within different movements. When intersectionality was not yet at the center of the conversation and human rights activities were in siloes, the gender and disability initiative has been providing substance, contents, practical examples, and powerful voices to advocate across women’s rights, rights of persons with disabilities, and global development agenda. Experiences of women in their diversities have been heard and used as evidence to inform recommendations. By focusing on successful and replicable practices, MIW has been a tool to allow empowered women with disabilities to inspire and provide guidance to governments, national and local actors, on how to effectively tackle the human rights violations that they face.

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Part VIII

Inclusive Design and Accessibility

Inclusive Design: Valuing Difference, Recognizing Complexity – Introduction

44

Jutta Treviranus

Contents

Abstract

Inclusive design demands a change in mindset. The theory and practice of inclusive design contest the assumptions regarding such fundamental concepts as success, evidence, value, truth, expertise, intelligence, completion, quality, scaling, prosperity, benefit, planning, and consistency and their associated conventions that lead to vicious cycles of disparity and inequity. Current society's assumed notions reduce diversity and deny complexity. This chapter outlines the theory and practice of the Canadian school of inclusive design, the assumptions

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that must be unlearned, and the guiding values that act as a generative framework. How this school of practice is situated within complementary fields is described. The chapter also provides an overview of the chapters within this section.

Keywords

Inclusive design · Diversity · Complexity · Uncertainty · Disparity · Equity

Introduction

Diversity is our greatest asset. Inclusion is our greatest challenge.

The framing of inclusive design reflected in this section (also referred to as the Canadian school of inclusive design) comes from the recognition of a fatal flaw in the current trajectory of our civilization, the responsibility and opportunity of designers, and the imperative to reframe design to counter this flaw. Initially the flaw has differential impact, sacrificing marginalized minorities to increase the advantage of privileged majorities, but it will lead to the unravelling of the whole. Each advance, each innovation, each idea of progress has widened the cracks and stresses in the complex adaptive system that is our human endeavor. This flaw is entrenched in what and who is valued and rewarded; our civilization's sense of truth, evidence, and proof; how decisions are made and who makes them; how our society educates and employs workers; how things are designed and who they are designed for; and what lives are deemed livable and recognized as human. With globalization and colonization, the flaw is played out in both the Global North and the Global South with the Global South experiencing more intense harms.

Jagged Edges of the Human Starburst

I have described and illustrated the flaw (and the inclusive design approach to counter the harm) using the concept of a human starburst (Treviranus, 2018a). Over 40 years I have collected data regarding what people need to participate fully in our human systems. The only way to visualize or plot this data is as a three-dimensional multivariate scatterplot. This resembles a "normal distribution" or a starburst. I have termed it the "human starburst" (Fig. 1). Approximately 80% of the needs are clustered together in the middle taking up 20% of the space, and the remaining 20% are distributed throughout the jagged periphery covering the remaining 80% of the space. The needs in the middle are close together or more similar, and the needs at the jagged edges are furthest apart, meaning more different (Fig. 2). This reveals a pattern in our society's approaches to design and in societal

Fig. 1 A multivariate data plot in two dimensions of the diversity of needs of a population of people. (Attribution-NonCommercial 4.0 International License with attribution to the Inclusive Design Research Centre, OCAD University)

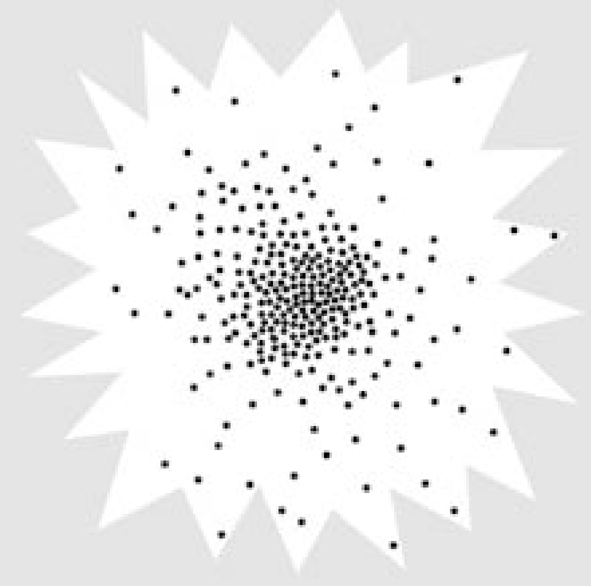
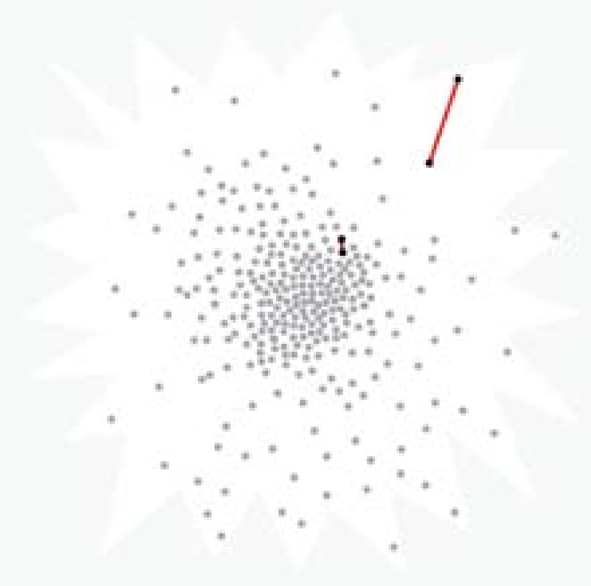


Fig. 2 The starburst plot shows a denser set of dots (representing the majority needs) in the center and more widely spaced dots the further you get from that center (the minority needs). Distance represents difference. The closer the dots, the more similar they are. The wider they are spaced from each other, the more they differ. (Attribution-NonCommercial 4.0 International License with attribution to the Inclusive Design Research Centre, OCAD University)



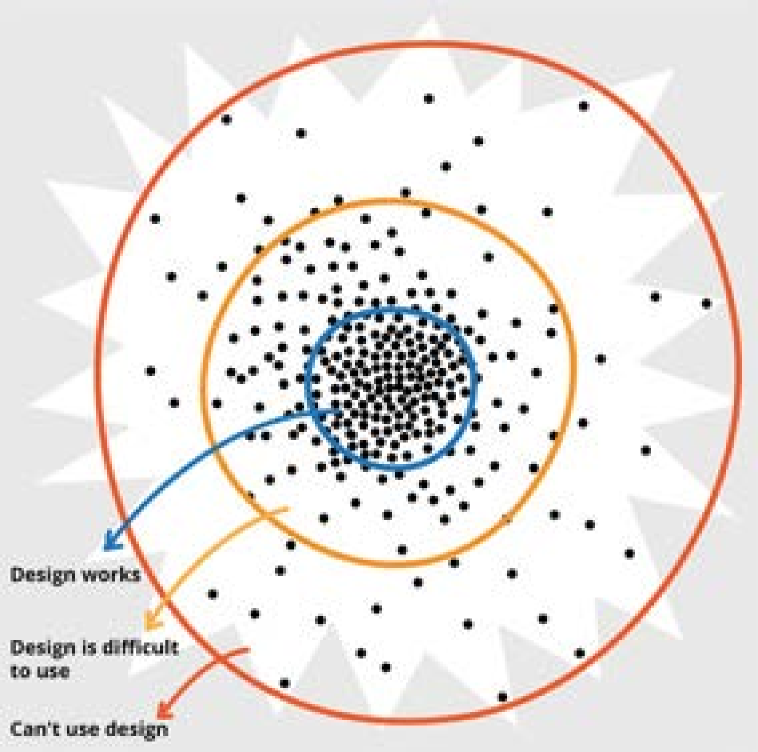


Fig. 3 Design works for needs in the middle become difficult to use as they stray from the middle and don't work for needs at the edge. (Attribution-NonCommercial 4.0 International License with attribution to the Inclusive Design Research Centre, OCAD University)

production of knowledge or assertions of sanctioned truth. Designs of products, services, environments, or systems generally work for needs in the middle and are more difficult as your needs move from the middle, and designs do not work if you find your needs at the periphery of the starburst (Fig. 3). Similarly, the established truths, proven by statistics, hold for the middle, are inaccurate if you stray from the middle and are wrong for people whose needs are at the jagged edges (Fig. 4). The only common data characteristic of disability is sufficient difference from the average or norm that systems do not work for you. Disability is at the jagged edge of the human starburst.

Widening Disparity

These patterns set up and sustain vicious cycles of widening disparity that ripple through and affect all our societal systems and all aspects of people's lives (Fig. 5). Due in part to economies of scale, products needed by people with needs at the edge

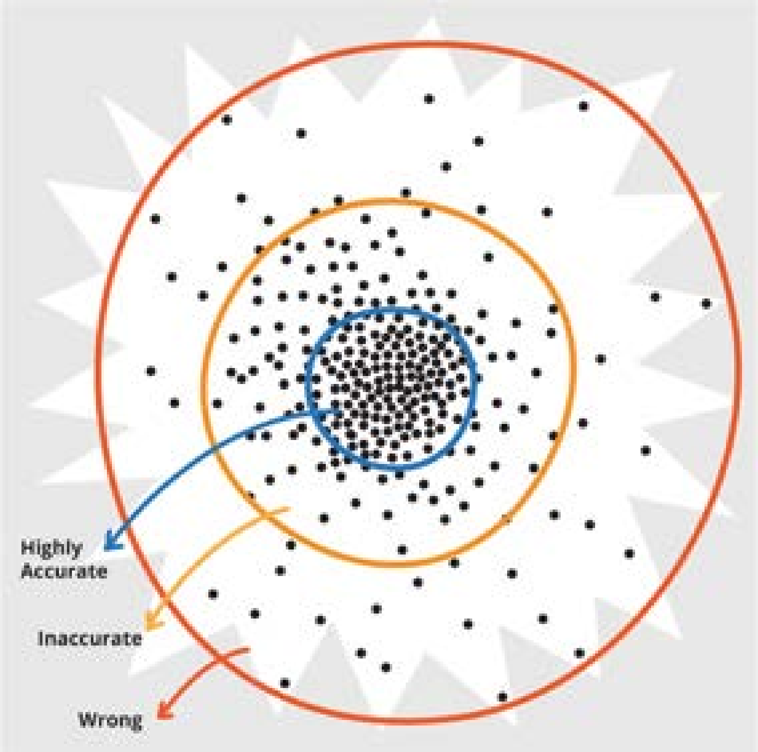


Fig. 4 The established truths, proven by statistics, hold for the middle, are inaccurate if you stray from the middle and are wrong for people whose needs are at the jagged edges. (Attribution-NonCommercial 4.0 International License with attribution to the Inclusive Design Research Centre, OCAD University)

cost more, are less available, and are less reliable. If a person requires alternative access systems to access digital devices, for example, the needed access devices can cost up to ten times as much, they will not interoperate with many essential applications, and they will not be updated as frequently to keep up with the changes in the essential applications they need to control. This means that disabled people[1] cannot adequately participate in and thereby influence the digital economy. Academic impact metrics used to qualify for academic positions and funding favor publishing in high impact journals. These prefer research that shows statistical power. Outliers and diverse minorities will not garner statistical power. Conclusions

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[1] How we describe people with disabilities or disabled people is contested, complex, and reflects a history of stigmatization and marginalization. As inclusive design recognizes the lived experience of disability as a source of valuable expertise, I have chosen “disabled person” or “disabled people” in this chapter. This is not to deny the values reflected in people-first language.

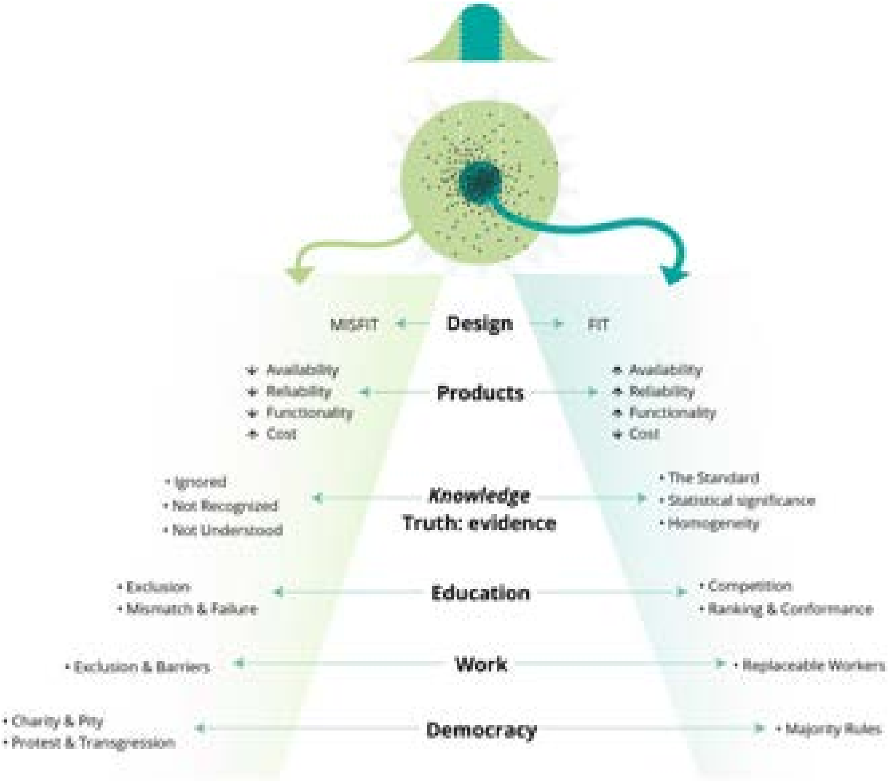

Fig. 5 The people whose needs are out at the edges face vicious cycles of disparity that affect all aspects of their lives, including education, employment, digital inclusion, representation in media, and even representation in democratic decision. (Attribution-NonCommercial 4.0 International License with attribution to the Inclusive Design Research Centre, OCAD University)

or findings from research to understand the needs of disabled people are not generalizable and will not meet the impact metric needed to obtain funding Pfeiffer (1993). Scholars concerned with disabled people will be less likely to receive tenure or be promoted. These values are perpetuated at every stage of life and every sector of society. Education is designed to create standardized students ranked on the same scale. Employment is designed to recruit replaceable workers. Politics is designed to attract attention and appeal to the largest number of voters. The reduced democratic ideal functions using majority-rules decisions. Without asserting fundamental rights for all, this means that the trivial needs of the majority will overrule the critical needs of the minorities. Responsible and evidence-based governments make budget decisions based on formulaic measures that have an impact on the largest number of citizens.

Disabled people feel the extreme edges of these vicious cycles, increasing the vulnerability to poverty, isolation, health risks, and other harms Harris (2023).

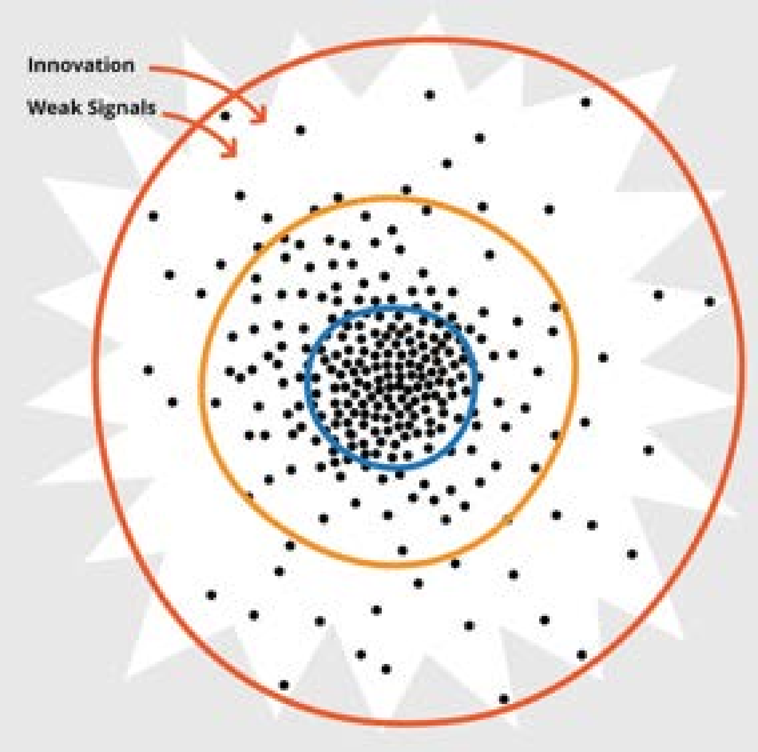

Fig. 6 People with needs at the edge are the greatest sources of innovation. They are also the most likely to detect the weak signals of risks to come. (Attribution-NonCommercial 4.0 International License with attribution to the Inclusive Design Research Centre, OCAD University)

Scholarship into ways to address the harms is sparse and inaccurate beyond the research subjects. Services and social safety nets are inadequate and precarious. Available services frequently assume homogeneity in serving people who are extremely heterogenous. These “social safety nets” often invest more in policing to prevent suspected malingering than they do in offering needed services. However, it is out at the jagged edge that you find the greatest innovation and the earliest warning signs of emerging risks (Fig. 6) Rose (2015).

Old Ideas and Innovation

Progress, innovation, or technological advances have only intensified these patterns. It can be argued that our current notions of innovation, progress, and design are still in the thralls of the thinkers of the 1800s. Among these persistent influential ideas are Quetelet’s notion of the average human as the norm to aspire to (Quetelet, 1842; Grue & Heiberg, 2006); the social Darwinist’s misinterpretation of evolutionary theory, mistakenly identifying the “engine of evolutionary advance” as survival of the fittest and winner-takes-all zero-sum competition (Spencer, 1852); the appropriation of Pareto’s 80/20 principle to justify ignoring the difficult 20% that require 80% of the effort (Koch, 2011); or the bigoted and hierarchical categorizations of humans in Melvil Dewey’s classifications of human knowledge (Wiegand, 1996). These are bolstered by the economic and political thinking of the Gilded Age, industrialization, capitalism, and the industrial model of schooling – re-costumed in later neoliberalism.

The proliferation of artificial intelligence relying on statistical reasoning to guide and make decisions amplifies, accelerates, and automates these discriminatory patterns (Gupta & Treviranus, 2022; Treviranus, 2022). AI automation removes the option to make exceptions. Mechanizing decisions such as hiring, academic admission, loans, medical triage, urban planning, security, probation, and determination of parental fitness, among other critical decisions, exonerates the implementers of the harm these decisions do to outliers and marginalized minorities. One positive side effect of AI is that AI makes manifest the potential harms, such that these harms gain the attention of hard scientists and cannot be dismissed as unempirical soft science.

The Dilemma of Hill Climbing

To counter this dominant entrenched pattern requires a complex adaptive system understanding. Complexity theory offers the hill climbing model to demonstrate the dilemma we face as a civilization. Think of our collective human journey through history as navigating a complex, unpredictable, changing terrain of mountains and valleys that is shrouded by fog (Fig. 7). One of the dangers we face is flooding, and the water level is rising. To survive as a species, we need to find a generous high place that has room for all of us. Unfortunately, we are stuck on a small, steep spiky mountain. In our attempt to get to the top of this small mountain, we are eroding the slope, making it harder for many people to climb out of danger and destroying everything we need to survive in the long term. Because the hill is steep, and space is scarce, we think we need to compete. We believe that if one of us makes it up, others must come down, and when others win, we lose. The popular and respected message is that safety and success are to go higher up. We are told that to succeed we need to do what we have been doing more effectively, efficiently, accurately, and consistently.

The tragedy is that within the same terrain there is a large generous mountain that could fit all of us and that won’t be submerged. However, to get to it we need to reverse direction and go against much of what we have been taught, all the formula we think will lead to our success. Rather than going up our local steep mountain, we need to go down to find the more generous higher plateau where we can collectively survive and thrive. We have been taught that going down is failing, dangerous, and shameful. To reach our destination we also need to collaborate rather than compete

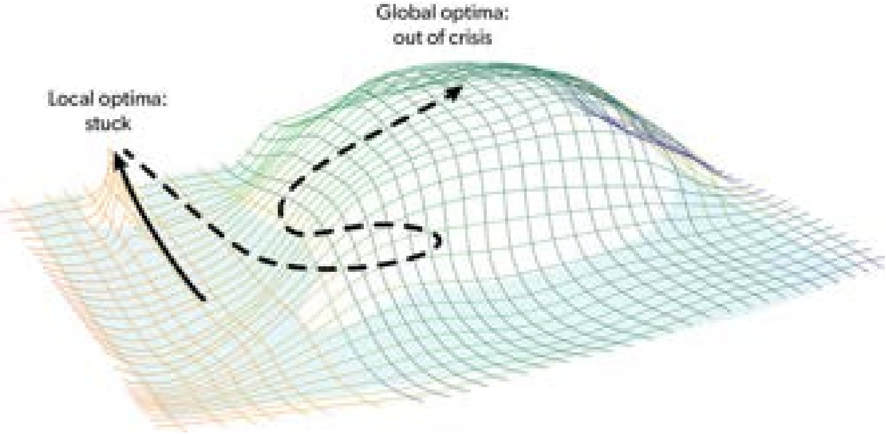

Fig. 7 As a civilization we are hill climbing a local optimum. Rather than doing the same thing more efficiently, consistently and accurately to climb a local optimum, survival requires reversing course to find the global optimum. (Attribution-NonCommercial 4.0 International License with attribution to the Inclusive Design Research Centre, OCAD University)

and seek our collective success because to make it we need as many diverse views as possible. We need to listen to the people that are currently at the bottom. They are closest to the place we need to go, collectively they have the best sense of the most promising terrain, and they also have the best view of where the rising water is. This is hard for most people to do because the people at the bottom have been denigrated and labelled as failures. Our systems of communication, navigation, education, transportation, reward, and valuation have been designed to exclude them. Our respected systems of knowledge and evidence don't support them. We have broken their trust. We have sacrificed them in the rush to progress up our steep hill. In the process we have chosen to create systems that won't work for us when we are vulnerable, and we will all be vulnerable.

Lessons of the Pandemic

The pandemic has highlighted the fault lines in our systems. For some it became clear that "none of us are safe until all of us are safe," that attending to the vulnerable was needed to secure the common good (United Nations, 2020). For short periods there was a public understanding and demonstration of the phenomena that if we design to include people who are most vulnerable, we are compelled to create systems that work for us when we are inevitably all vulnerable. However, there was powerful resistance to these insights and a resurgence of social Darwinism (Nachtwey & Walther, 2023). Public administrations produced messaging that assumed homogeneity and argued that simple, consistent messaging was needed when the conditions and vulnerability were anything but homogenously distributed. Rather than change course, we have collectively reverted to old patterns.

Harmful Patterns in Accessibility Field

Even the accessibility field has adopted the same harmful patterns. Notions of enforcing "full accessibility" by complying to a finite checklist of design criteria deny the extreme diversity of disabled people, and the neglected needs of people are not represented in the accessibility checklist A11y Project (2013). Presenting deadlines for reaching "full accessibility" denies the complex adaptive system in constant flux that presents new barriers with every update. Web accessibility has grown a checking and repair industry dependent on the existence of the barriers, demotivating bold measures to eradicate the problem.

Laws have been crafted to support a segregated assistive technology industry, making it almost impossible to achieve interoperability in the digital realm. Given the small customer base of each product, assistive technology companies often cannot support good user experience design, training, or setup (Treviranus, 2018e). The promotion of assistive technology as a solution to accessibility ignores the fact that there is no assistive technology market in most of the world. In most countries AT is not sold, there is no training available, or AT costs more than 50% of an annual salary (World Health Organization, 2022). Digital AT such as screen readers, refreshable Braille displays, captioning, speech recognition, alternative keyboards, or word prediction are not available for most languages other than English. The promotion of a segregated market by the Global North takes the responsibility and onus away from mainstream manufacturers to address edge requirements and denies all consumers the accessible choices when they face barriers. It denies the global market of the assistive technology features needed by disabled people to access digital systems.

The Three Dimensions of Inclusive Design

To address the flawed patterns, the field of inclusive design has resisted and contested favored and entrenched forms of scientific method and democratic majority rules governance that is not accompanied by strong human rights commitments, capitalist economic theories, notions of academic rigor, forms of formal education, production, success, solutions, and progress. The field has found itself at odds with the framing of "full" accessibility and rigidly bounded human categorization in equity efforts. This inclusive design practice is also concerned by the rift between academic scholarship intended to benefit disabled people and their communities and the people and communities themselves, caused by the complex, academic expression of ideas and concepts.

Inclusive design is an evolving, adaptive field that resists dogma or doctrine. There is no set of criteria, no cardinal listicle of principles for success. Measures of success are seen as relative to the individual, the goal, the system, and the context. However, the practice is anchored by a set of values expressed as the three dimensions of inclusive design (IDRC, n.d.).

The first dimension is recognizing that we are all different and that this diversity is the true fuel of evolutionary advance. It is our greatest asset. Given the uniqueness of individuals, especially the diversity of disabled people, each person must be supported as experts in our own difference Treviranus (2021). Generalizable claims do not hold at the edges. This vast range of differences needs to be addressed in an integrated and not segregated way.

The second dimension is that the process of design must be inclusive. People who are the intended beneficiaries, and specifically individuals with the greatest challenges, need to frame the problem and codesign the process of designing, as well as the approach to addressing the challenge. Inclusive designers need to continuously ask who is missing and who have we left behind with this innovation.

The third dimension is recognizing that we live in a complex adaptive system. We need to design systems that provide benefit for all. No inclusive approach will survive if it doesn’t ultimately benefit the system as a whole. Any approach will erode if we don’t attend to the dependencies and nested layers of the system. Nothing is done in isolation. Everything is entangled and variable. Problems are not monocausal; the path out of problems is not linear or formulaic. There is no fix, solution, or success; it is a continuous process. But it is the people at the margins that are most familiar with the risks and opportunities.

We, the Canadian school of inclusive design, apply these dimensions in what we call the Virtuous Tornado (Fig. 8) Treviranus (2019b). Unlike the design thinking squiggle (Newman, n.d.) which iterates to a winning solution (or the UK School design waterfall) (Clarkson et al., 2007), we cocreate an adaptable system that stretches to encompass more and more of the missed needs, by asking at each design iteration “who are we missing?” Each iteration builds upon small successes, providing opportunity to try out and constructively critique (Inclusive Design Research Centre, n.d.-a, n.d.-b). We appreciate the imperfect, impermanent, and incomplete and know that mistakes and failures yield the greatest learning Treviranus (2010). We also contest the traditional notion of scaling or the formulaic replication of a “winning” design. We recognize that any inclusive design system must be scaled through diversification. Traditional scaling of technology developed in the Global North to the Global South replicates the colonial hubris of the past. The designs and implementation must be community led and bottom-up.

Practicing Inclusive Design

The following section describes the practice of inclusive design applying the three dimensions in greater detail. These practices are adapted, localized, and contextualized according to the people that will be impacted by the decisions and the contextual environment and goals.

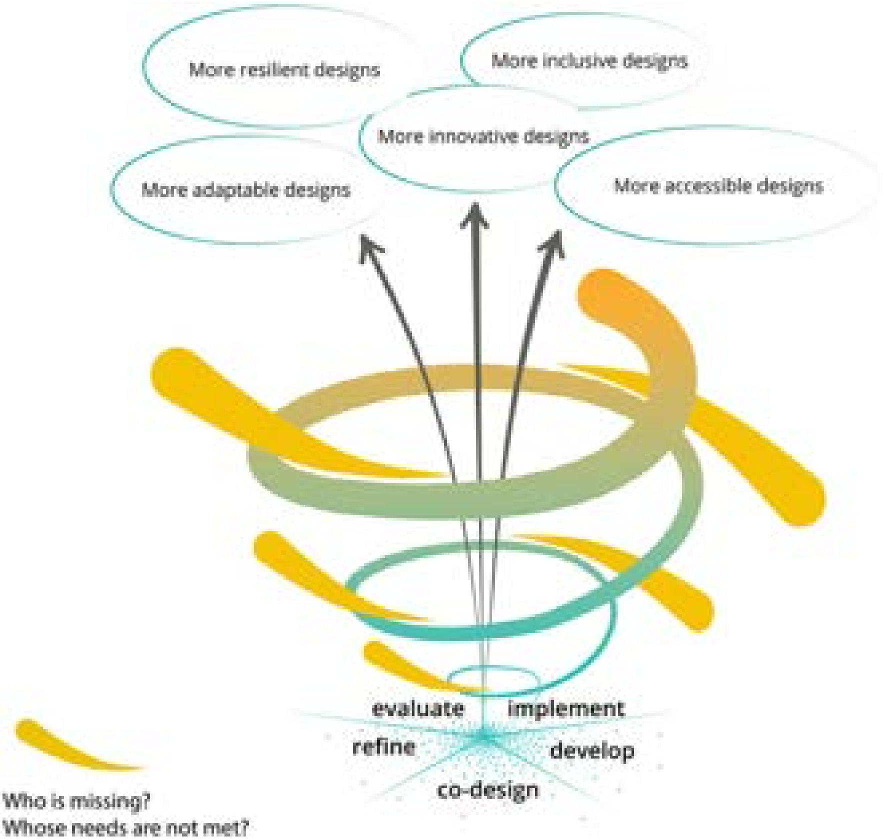

Fig. 8 The Virtuous Tornado is an iterative planning process. Once the initial needs are identified by individuals and communities the cycles begin, iterating further and further to the edge, injecting further needs and characteristics at each cycle, constantly recalibrating and evaluating progress, and asking "who are we missing" to recruit the necessary knowledge and lived experience still to be included. (Attribution-NonCommercial 4.0 International License with attribution to the Inclusive Design Research Centre, OCAD University)

Dimension One: Human Difference and Variability

Value Human Difference or Variability

The first dimension is to recognize that we are all different, variable, and unique (Treviranus, 2018b). This diversity is valuable. Traditional design, planning, and decision-making processes attempt to reduce that difference and variability to simplify the process. The range and spectrum of difference are conventionally reduced to an average, the most profitable, the most popular, or the most powerful. All these forms of reduction lead to ignoring and devaluing the spectrum of diversity and the needs and strengths at the edges experienced by the people who will feel the greatest impact and offer the greatest insights.

Discover the Full Spectrum of Needs and Traits

Inclusive design research and planning do not attempt to find the statistical average, the highest incidence disability, the easy wins, the highest return on investment, or the winning vote. Inclusive design seeks to understand the full spectrum of differences and range of variability, making sure not to miss the needs and strengths at the edges of the human starburst that have not been served by existing designs. The needs at the edges will include and encompass the average needs at the center of the starburst.

People Are Multifaceted

In recognizing the full range of difference and variability, inclusive design does not sort needs and characteristics into predetermined categories, classifications, taxonomies, diagnoses, or identity groups and prescribe approaches or base assumptions on these categories. Lived experience is individual and cannot be boxed; no two lived experiences will ever be the same. Lived experience includes many intersecting factors including identity, culture, gender, age, ability, and contexts. Take, for example, the experiences of a person who is blind. One person who is blind will have different experiences than another person who is blind, not only because they have their own unique life contexts (where we grew up, cultural background, etc.) but also because blindness is experienced differently. For instance, someone with acquired blindness who has experienced the world with sight will have a different lived experience in the world than someone born blind. Even from a functional perspective, does the person read Braille or prefer speech? What are their language preferences? And importantly, lived experience can only be expressed by the person who is living the experience.

This sorting and labelling of humans often means that people fall through the cracks or are stranded at the edges. People that don't fit the available categories are disadvantaged or forced to deny their differences and conform. Organizational structures used in inclusive design are supportive structures, akin to trellises, which prompt further generative exploration. Inclusive design research seeks to explore the edges and the deeper connections rather than reduce to the average or dominant characteristics.

Recognize the Ownership of Knowledge and Expertise

Professional expertise usually focusses on the average traits, probabilities, and dominant patterns. By its very nature professional expertise cannot encompass the jagged edges of the human starburst. Only the person themselves and the trusted people that are closest to them hold the unique expertise regarding requirements at the edge. Inclusive design recognizes that they are also the rightful owners of this expertise. All data about a person should be governed by the person, and the value derived from the data should vest with the person that is the subject of the data.

Integrate to Benefit All

When discovering the range of differences and variability, the goal is to arrive at integrated, adaptable systems to address the full spectrum of needs. If the edge requirements are treated as separate or special, requiring segregated approaches, those approaches will lack interoperability, and they will lack the investment needed to keep them current. Segregation also means that the majority will not benefit from the innovation and risk detection Kemper et al. (2010).

Dimension Two: Inclusive Codesign Process

Codesign with and by the Edges

For all design efforts, the greatest innovation and the best means of risk prevention is achieved when persons that have the greatest difficulty with the current state or who are currently excluded guide the design. Rather than designing for individuals who face barriers to access, which entails a presumption of knowing what people need or what will work best for them, inclusive designers support the people that will be most impacted by the design in codesigning the approaches to address barriers (Treviranus, 2018c). This may entail equipping a community that has experienced marginalization to lead a codesign process (e.g., community-led codesign), or bringing together groups of people who have experienced barriers with other helpful expertise to address a design challenge. The value of the insights and expertise contributed must be remunerated or compensated at the same level as other expertise.

Codesign the Design Process

Inclusive codesign is not achieved by inviting people to a process that is not designed with them in mind. This puts the invited participants at a disadvantage. Codesigners should be invited to help determine what process will be used, not only the outcome.

Make Sure the Design Tools Do Not Exclude

Many commonly used design tools are inaccessible. Many design tools are visually biased with no alternative ways of expressing or receiving the information. Often tools use insider language and terms that are not understood by people unfamiliar with the process. Many design conventions create typical persona or profiles that exclude the atypical. They competitively attempt to find “the best” approaches, compromising the needs not addressed by the best approach. Ensure that the tools used are not biased against people at the edges.

Find Deeper Commonality that Includes the Edges

In a group design process, it is human nature to attempt to find commonalities, affinities, or points of connection. People with needs at the edges of the starburst will have fewer shared needs or traits within a group and will often be left out. Inclusive design practice encourages finding deeper commonalities across the range of differences that include the individuals with needs at the jagged edges of the starburst. Rather than superficial affinities or obvious shared traits, inclusive codesign encourages participants to find fundamental human goals or needs that are shared across established divides.

Seek Diverse Perspectives

It is a well-documented phenomena that including diverse perspectives leads to better planning prediction and innovation (Page, 2007). This includes perspectives that may be viewed as dissonant or foreign to the culture of the organization and people with backgrounds and perspectives that have not been previously included. Inclusive design does not seek "culture fit" but "culture add." Constructive critique, an alternative, novel, or new perspective, is valued. This requires creating a respectful and caring space for potentially difficult discussions.

The one-size-fits-one system design sought in inclusive design is not the form of content personalization that shields users from diverse perspectives or recommender systems that only show us content from people like us. These forms of personalization lead to greater polarization and tribalism and demonization of people at the marginalized edges (Treviranus & Hockema, 2009). Inclusive design seeks to create an environment that makes room for a diversity of respectful views.

Who Frames the Challenge, Problems, and Goals?

The focus of inclusive design is not technology looking for an application or a hypothesis looking for verification. The parameters of inclusive design research and the research plan are not predetermined. The challenge, the associated problems to be addressed, and the goals of the design process are collectively arrived at by the codesigners. The aim is to design a system that encompasses as far out to the edges and as many edge requirements as possible. The best authority regarding these requirements are the people that have lived at the margins. Their perspective is needed to frame the challenge.

No Winners and Losers

In most forms of design, when a choice is to be made, competitive selection is used to find the consensus selection or the majority opinion. This common process entails inevitable compromises to find the "best" solution or the winning option arrived at by consensus. Most often people who are highly unique or have minority or outlying needs are the individuals asked to make the biggest compromises or left without viable options. Competitive selection inevitably means there are winners and losers. Whether through voting with majority rules criteria or less formal prioritization, it is usually the individuals with highly diverse needs at the edges that lose out. Rather than finding a winning solution, or a best practice, inclusive design is guided by diversity and flexibility and aims to create a system or infrastructure that can encompass the edge requirements identified in codesign. What is the range of adaptation needed? What are the choices that should be included?

No Solution or Fix

The deeper challenges addressed through inclusive design cannot be fixed or solved and then dismissed. There are inevitably requirements that have not been considered, unpredicted changes in the context, or ripple effects of design choices that create new considerations. Declaring that a problem has been fixed does harm to individuals that are still excluded. It reduces the vigilance needed to prevent emergent threats to inclusion and further harm. It also reduces awareness of emerging opportunities to find better approaches. Inclusive design is a continuous practice and process.

Understand the Value of Mistakes and Failures

Inclusive design involves acknowledging mistakes and failures. More importantly it involves understanding the learning value of mistakes and failures. Inclusive design also recognizes that today's solutions can become tomorrow's problems. It is easy to get carried away with considering the opportunities without also thinking about the risks.

Ask Who Is Missing and Iterate Toward the Edge

Inclusive codesign is an iterative process. Each iteration produces a design that can be evaluated by individuals with lived experience of the barriers. At the end of each iteration, the codesigners ask: "what perspectives are still missing" and "whose experience might be compromised by the design choices we have made?" These perspectives are sought to codesign the next iteration (Fig. 8).

Dimension Three: Designing in a Complex Adaptive System in Flux

Be Aware of the System

No design decision is made in isolation, and the impacts of all design decisions are felt well beyond the intended users (Treviranus, 2018d). Our world is a complex adaptive system in constant flux. Interactions are becoming more entangled and complexly connected. Actions are rife with feedback loops, viral phenomena, and multifaceted "externalities." Challenges are not just complicated; they are complex. They are not amenable to engineering or linear logic models. Most problems are not mono-causal or simple.

People with needs at the edges feel the greatest effects of both vicious and virtuous cycles. Like a spinning platform, the edges travel the furthest. Counter to fears, including and respecting edge perspectives do not lead to extremism or greater polarization. Respectfully making room for more than two sides to an issue leads to greater equilibrium.

Inclusive designers seek an understanding of the system that is the context of any design decision. Inclusive design research comes from as many perspectives as possible: bottom-up, top-down, inside-out, and outside-in. How are things connected and related? What are the assumptions being made? What are the value systems at play? Are there other ways of knowing that are being missed? Most importantly inclusive design considers the conventionally missed or devalued perspectives.

Beware of Cobra Effects

Cobra effects are the unintended consequences of oversimplistic "solutions" to complex problems. First coined by the German economist Horst Siebert, the term refers to an anecdotal tale of bounties for dead cobras to eradicate cobras in

New Delhi (Siebert, 2001). As the story goes, many cobras were turned in, and the program was considered a success. When the bounty was ended, cobra breeders, a new occupation incentivized by the bounty, no longer had a market for their cobras and released them leading to an increase in the cobra population. Not only did the program fail to incentivize the desired outcome; it also used measures of success that were misleading and failed to assess the program in a useful way.

There are many examples of cobra effects in the e-accessibility domain. Rigid and static accessibility policies that do not keep pace with contextual changes may result in more attention being paid to being granted exceptions to accessibility requirements than to how to achieve accessibility Treviranus (2019a). Accessibility certification of organizations that does not encompass edge requirements often makes it harder for people with edge requirements to request the actions needed to attain access. Accessible designs of tests of human skill or knowledge that do not consider the cognitive load of the access method can cause more harm than empowerment. Inspirational stories of overcoming barriers or miraculous new inventions that do not consider poverty or availability can make it harder for excluded individuals to advocate for access.

Go Deeper and Broader

Often the symptoms of a problem or barrier are very superficial or specific. Like a home renovation project, the symptoms are usually indicators of much deeper problems. Fixing only the superficial symptoms will hide the deeper issues and result in greater harms in the future.

Inclusive designers engage in processes to uncover the deeper origins of problems. One method is to ask successive “whys.” This is referred to as the “toddler-grandparent conversation,” after the insatiable curiosity of toddlers who are not satisfied with a simple answer (IDRC, 2015). The aim is to discover the depth of the issue and to assess whether the codesign team is empowered and resourced to make the required changes. Even if the underlying problems are not within the control of the team, awareness of the deeper causes will inform the design and help set an agenda for advocacy.

Discover the Friction Points

Even the most brilliant accessible designs will encounter friction points. Our complex systems tend to have nested domains of influence. Each layer of influence needs to be addressed, or the accessible approach will be eroded and eventually fail or be abandoned. The persons at the boundary between the changed layer and the unchanged layer will feel the greatest friction. For example, a new accessible curriculum approach for a given student requires the support of the teacher, who needs the support of the principal, who needs the support of the school board, who needs the support of educational authorities within the government. The parents and the community also play a role. The larger and more beneficial the change, the greater the threats to survival if the various levels of potential friction are not addressed.

Recognize Potential and What Is Possible

Favored research methods, such as statistical reasoning, including artificial intelligence systems, use empirical data as evidence and facts Trewin et al. (2019). Data is inevitably about the past. Evidence-based decisions are guided by past successes and designed to optimize the conditions that led to past successes. People who have edge requirements are far removed from the optimal patterns. Optimizing patterns of the past also amplifies past discrimination.

Inclusive design seeks to cocreate new knowledge, explore the data gaps, the past mistakes and what they reveal, the unmet needs, the devalued strengths, the counterintuitive, and the unexplored spaces between well-established knowledge domains. Inclusive design inverts power hierarchies to find the missed perspectives. One example is the inverted word cloud (Li, 2021) which centers and increases the size of unique, novel, minority words or phrases rather than the most popular words and phrases.

Inclusive design research is through trial and error of potential designs. Needs and conditions at the edges of the human starburst are not well understood by established research systems. Statistical reasoning leads away from outliers. Academic publishing in fields concerning humans frequently demands statistical power. This cannot be achieved when gathering data about edge requirements. Rather than optimizing past successes, inclusive design focuses on potential and possible approaches and creates iterative prototypes to enable testing in the “wild” and continuous improvement.

Scale by Diversification

One of the final stages of traditional design and development, and a conventional signal of success, is to scale the winning solution. This usually entails formulaic replication of the competitively chosen design. This form of scaling does not respect the diversity of contexts or circumstances. Often it is a form of modern-day colonialism.

Inclusive design iteratively codesigns a system that can be scaled by diversification and adaptation, not formulaic replication. If it is a software architecture, for example, it is designed to adapt, interoperate with different interfaces, translate to different languages, and work with as-yet-unthought-of personal needs and preferences. This usually entails open and transparent development that supports customization, user-continued design, and contributions from an open community Watkins et al. (2020).

Recognize the Importance of the Experience of Vulnerability and Fragility

During times of crisis, there are frequently arguments to sacrifice the vulnerable or weak for the progress of the species. This is purported to be the natural course of evolution. However, the fuel of evolutionary advance is diversification. It is during times of relaxed selection and diversification that the human species has progressed (Deacon, 1997).

Some technology leaders propose that technology can design away human flaws, including disabilities through innovations such as genetic engineering. At the most extreme, this leads to eugenics. This form of reasoning results in monocultures. Monocultures leave the species with few evolutionary choices when an unexpected crisis arises. Inclusive designers recognize that when we design our systems to work for people who are vulnerable and fragile, we prepare our systems to work for all of us when we inevitably find ourselves vulnerable and fragile.

Situating Inclusive Design

The approaches to design and disability are many. Even the term inclusive design has been used by two fundamentally different but related approaches or schools. Both are responses to universal design Mace (1997). The UK school adopted the name inclusive design as a realistic approach to universal design to encourage and support the broader adoption of accessibility features by businesses (Keates & Clarkson, 2002).

Clarkson et al. in the UK identified high incidence disability barriers, the design features that would address these barriers, and the impact on the overall customer base (Clarkson et al., 2003). From the perspective of the starburst, they argued for an expansion of the middle to encompass needs that were closer to the middle while maintaining the same business values of increasing return on investment (Clarkson & Coleman, 2010). They supported the business case for greater inclusion and "met designers and businesses where they were at." The UK school grew out of architecture and industrial design which have the constraint of choosing a single design to meet the needs of the largest group but has since encompassed digital inclusion.

The Canadian school of inclusive design was established simultaneously but emerged from digital design (IDRC, 2021). In a sense the Canadian school saw universal design as a situational compromise to the goal of a vision of inclusive design that valued human diversity. The Canadian school saw the possibility of foregoing the compromise required in choosing a single universal design required in static systems such as buildings and mass-manufactured products. The school recognized that digital systems offered the possibility of moving from a one-size-fits-all product to an integrated system that offered one-size-fits-one choices in response to human diversity and uncertainty. Rather than relying on statistical reasoning and privileging homogenous numbers, the Canadian school stressed the need to, and value in, prioritizing and iterating with or by people at the jagged edges. The Canadian school demonstrated that people with needs at the edge were the source of the greatest innovation and most aware of the weak signals of emerging threats. The Canadian school employed complex adaptive systems theory and applied inclusive design to a full range of systems, including social systems, organizational structures, services, governance systems, cities, markets, and technical systems. The school adopted Ursula Franklin's definition of technology as "technology involves organization, procedures, symbols, new words, equations, and, most of all, a mindset" (Franklin, 1999).

These two schools are complementary and have found their way into related emerging fields such as the European Design for All framework (Eikhaug, 2004).

The field of inclusive design continues to evolve in response to a changing and unpredictable context. There is a commitment to humility. The framework reflected in this section is intended to support generative growth, rather than constrain practice.

Part Overview: Diversity of Perspectives and Implementations

The chapters in this section reflect the diversity valued in inclusive design. Inclusive design requires a significant culture change. The practice contests conventions within the domains of research, development, markets, education, employment, and design itself. It is practiced within systems that are frequently a mismatch with the values of inclusive design. The process of culture change is therefore iterative, taking into account the degree of change the system will tolerate without provoking a backlash. The current practices of inclusive design cover a broad evolutionary spectrum. Some practitioners have the freedom to implement processes that reflect the least constrained values of inclusive design, while other practitioners must "choose their battles" to stretch the domain within which they operate. One of the most constraining domains is academia. The notions of what constitutes evidence, proof, knowledge, and truth and what has scholarly value within the current academic domain are biased against individuals who are minorities and outliers and systems that are complex and unstable. The sanctioned means of showing value and avoiding dismissal within the academic ecosystem often require customization of the practices of inclusive design, especially for emerging researchers.

Culture change and the evolution of a field can be constrained by proprietary practices and dogmatic insistence on adherence to standard criteria. The practice of inclusive design recognizes the value of the imperfect, incomplete, and impermanent. Perfection, completion, and stasis discourage adaptation, growth, and the participation of diverse perspectives. The Canadian school has no certification of quality or professional license, recognizing that standardizing the practice discourages continuous improvement, contextual adaptation, and learning from mistakes. (A counterargument is to prevent the use of the term "inclusive design" for superficial, diluted, and performative practices as the practice gains popularity. However, the risks of rigid standardization are greater than the risks of dilution.) The values of inclusive design are a compass to travel forward, and the practices are generative models that scaffold growth. Inclusive design is not owned or governed by any one group. This means that new practitioners can make it their own and adapt it and translate it to their unique context Adobe Inclusive Design (n.d.), Microsoft Inclusive Design (n.d.). The chapters in this section show a diversity of interpretations and attempts to adapt the practice to the context.

The coeditors of this section, Dr. Silvia Baldiris and Dr. Vera Roberts, have each contributed a coauthored chapter, from the Global South and the Global North. The section reflects only a small set of domains of current and potential application of inclusive design and the necessary adaptations shaped by contexts, individuals impacted, and challenges addressed.

Vera Roberts and David Pereyra of the Inclusive Design Research Centre in Toronto, Canada, in ▶ Chap. 45, "Inclusive Co-research with Experts with Disabilities," describe a form of codesign as co-research in which the individuals most impacted by the design are supported in taking an equal or leading role in the research and design decisions. The authors describe the application of an approach they have called appreciating, scaffolding, and keeping (ASK). Appreciating recognizes co-researchers as experts in their lived experience. Scaffolding supports co-researchers with the means to participate fully in the research process. Keeping accords ownership and builds capacity within the co-researchers and their communities in the research process and outcomes.

Silvia Baldiris et al., in ▶ Chap. 46, "CO-CREEMOS: A Strategy to Attend Diversity in Colombia," describe the important role of open access in supporting greater inclusion in education. Open Education Resources are instrumental in providing equitable economic access to educational resources, enabling the collective contribution and sharing of accessible variants of curriculum, and providing timely access to teacher resources needed to support students experiencing barriers to education.

Also on the theme of inclusive education and the role of open access, Raymundo Filho et al. describe the efforts to support accessible Open Education Resources (OER) as well as an accessible interface in the ProEDU OER repository in Brazil. They propose a model, titled accessible instructional design model (AIDM), to support OER life cycles or ecosystems that are accessible to students with disabilities.

Continuing this theme of inclusive education in the Global South, Elena Durán and coauthors in ▶ Chap. 48, "ICT to Support Inclusive Education in the Republic of Argentina," describe the current circumstances, the challenges, and the opportunities in Argentina as they relate to the many entangled intersectional considerations for students who face barriers and exclusion. They discuss the opportunities and risks associated with ICT in education. They delineate the complex and evolving circumstances within Argentina that have an impact on equity goals and the progress that has been made thus far.

Zoya Shepherd, in ▶ Chap. 49, "Inclusive and Equitable Education in Postcolonial Caribbean," explores inclusive education further, exploring the potential inherent in engaging teachers and students in cocreating more inclusive and robust local communities and the opportunity to transform education and ultimately the Caribbean society. She describes the challenges in an education system that perpetuates systemic segregation and the importance of student and teacher agency, flexibility, and creative thinking.

Virginia Rodés and Rigina Motz, in ▶ Chap. 50, "Interdisciplinary Center on Open and Accessible Educational Resources: 10 Years Building Inclusive Education in Uruguay and Latin America," complement these chapters with a longitudinal look at the work of the center in promoting educational inclusion, also stressing the supportive and necessary role of open education practices. They discuss the impact of the pandemic on educational gaps. Like other authors, they stress both the risks and opportunities of digital technologies, including the perpetuation of harm by digital colonization.

Karel Van Isacker, Petya Grudeva, and Maria Goranova, in ▶ Chap. 51, “Improving Inclusive Pedagogical Competences of Educators While Facing Pandemic Restrictions,” focus further on the impact of the pandemic on inclusive education but in the European context. They discuss the technical tools that received a boost during the pandemic and the benefits to certain students but risks to others. The authors also explore the opening of opportunities to further teacher understanding of inclusive pedagogy and a more inclusive educational mindset prompted by the disruption.

Jaime Hilditch in ▶ Chap. 52, “Pre-braille Implementation into Early Education: Tactile Activities to Introduce Braille Concepts to Kindergartners,” discusses the benefits to all students of introducing pre-Braille activities in early education. The author discusses the importance of play-based tactile exploration for developing tactile skills in all students and in developing Braille literacy for students who will use Braille. She describes the codesign and evaluation of a tactile pouch as an adaptable tool to prompt tactile exploration and understanding.

Brandon Biggs et al. in ▶ Chap. 53, “Remote Co-design in the Digital Age,” address the challenges and opportunities of remote codesign, made necessary by the pandemic. A set of resources, methods, and experiences are described in the context of four case studies of remote codesign sessions. The observations and insights gained can support engaging disabled people as stakeholders from any location around the globe in an inclusive design process.

Addressing employment barriers encountered by individuals on the autism spectrum, Mirjana Jevremovic, in ▶ Chap. 54, “Cocreating Inclusive Interviews: VR Technologies for Job Interview Training of Individuals on the Autism Spectrum and Strategies for Employers,” describes the codesign of virtual reality technologies and video self-modeling techniques to scaffold interactions between neurodiverse applicants, their support team, and employers.

James Aniyamuzaala in ▶ Chap. 55, “Inclusion of Persons with Disabilities by Design: From Product Centered to Justice and Person Centered Inclusive Co-design,” critically examines three schools of inclusive design and proposes a contextual expansion of the consideration of justice in inclusive design. He proposes justice- and person-centered inclusive codesign as a fourth school emphasizing social, political, economic, cultural, and technological justice.

Finally, in ▶ Chap. 56, “Compassion as a Tool to Enhance Communication Between Nurses and Children in the Oncology Pediatric Ward,” Tania Villalobos and her coauthors recount the exploration of inclusive design to address social and emotional connections and communication within a health setting. They recount the codesign of a communication tool in a pediatric oncology ward of a hospital in Mexico City. They stress the importance of cocreation with individuals impacted by the design.

Conclusion

The field of inclusive design evolves, adapts, and grows to address the complex emerging challenges, always asking “who is missing, who is facing barriers, how can we stretch to include, to the benefit of the whole.” The practice is anchored in values that invert power structures and determinations of worth. The tenets of inclusive design demand a different mindset and contest entrenched conventions. Resisting dogma, stasis, and boundaries, the practice adapts to the persons impacted by the design decisions, the context, and the goals. Inclusive design is founded on the tenet that it is when we are guided by the people at the edges of the human starburst that we can detect the earliest warning signs of challenges to come and we find the most authentic innovation needed to survive and collectively thrive.

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Inclusive Co-research with Experts with Disabilities

45

Vera Roberts and David Pereyra

Contents

Abstract

Existing co-research methods often limit participation and perpetuate exclusion of highly diverse populations. This chapter introduces an approach to co-design research that is inclusive and supports full participation of individuals with unique or diverse needs. Co-research is presented as having moved from the "design for" perspective to the "design with" perspective, and more recently to the "design by" perspective. Design by means that the population most impacted by the design is supported in creating the design. Inclusive co-design is a mindset that is applied in three ways: appreciating, scaffolding, and keeping (the ASK approach). Appreciating involves recognition of co-researchers as experts in their lived experience. Through scaffolding, co-researchers are supported and given the means to participate fully in the research process. Keeping gives ownership and builds capacity within the co-researchers and their communities in the

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research process and outcomes. Each of these three aspects are described in detail, building on our own experience from over one hundred inclusive co-design research activities, to provide guidance and approaches to other researchers who want to engage in inclusive co-design research.

Keywords

Co-research · Co-design · Participatory research · Disability research · Inclusion · Inclusive design · Accessibility

Introduction

Co-design is a commonly used approach for researchers and designers who want to use participatory research methods that enable diverse perspectives and viewpoints to inform design. Like Sanders and Stappers (2008), we view co-design as "the creativity of designers and people not trained in design working together in the design development process" (p. 12). Additionally, we understand co-design as "a practice where people collaborate or connect their knowledge, skills and resources in order to carry out a design task" (Zamenopoulos & Alexiou, 2018, p. 10). As inclusive design researchers, we recognize that everything is designed, and we think of design in the broader sense of planning with purpose. With this view, design is not limited to the look and feel or function of things; it can be more subtle, like design of a meeting or a policy. Given our definition of design, anyone who makes a decision that impacts others is a designer. Co-design, then, is useful across a broad range of activities and can be useful to individuals who do not normally self-identify as designers.

Sanders and Stappers (2008) explain that when conducting co-design research, the role of expert is switched from the designer to the individuals served by the design. Individual experience becomes the generative fuel for insights that can inform design. The role of the researcher is to support the expert by "providing tools for ideation and expression. The designer and the researcher collaborate on the tools for ideation because design skills are very important in the development of the tools" (Sanders & Stappers, 2008, p. 10). Similarly, research experience is important in the development of tools and the synthesis of insights from the co-design.

Existing Co-design Research Methods

While co-design research methods are an excellent way to gain diverse perspectives and improve design, most current co-design approaches perpetuate exclusion of highly diverse outlier populations through recruitment and research techniques that are inaccessible or that fail to account for diverse needs and preferences. Even when care is taken to invite diverse co-design researchers, researchers may not understand or learn about how those co-design researchers can participate fully.

Additionally, it is challenging to move from a "researcher as expert" to "the researched as expert" (Sanders & Stappers, 2012, pp. 23–24) power dynamic. It takes practice, commitment, and self-reflection to address power iniquities in the research process and across the research team. Co-design can slip into a traditional "researcher and researched" model without frequent monitoring and adjustments by the research facilitators. In the same way, it can be difficult for individuals who are not researchers to take on research roles, especially in the analysis and synthesis phases of research, when they have historically not been given opportunity to participate fully in research that impacts them.

Our Approach to Co-design Research

Inclusive Design Research Centre (IDRC) has been a leader in the field since 1993. We began with participatory methods that allowed for iterations based on user feedback but were based in a "design for" framework. We quickly moved to a "design with" approach and soon after realized that a "design by" approach best manifested the dimensions of inclusive design. This means that individuals who are most impacted by the design create the design. In the last 5 years, across multiple projects, IDRC researchers have carried out over one hundred co-design activities that followed this design by approach. Through these experiences, we have learned many lessons and have a great deal of knowledge to share with others wanting to carry out their own inclusive co-designs.

Inclusive Co-design Mindset

Inclusive co-design requires inclusive design thinking in all phases. Taking on a mindset of inclusive design (Inclusive Design Research Centre, n.d.-d) will support and enable inclusion throughout the co-design research process: recruitment, planning, tools, techniques, and analysis.

Co-design as a research and design approach stems from participatory research methods and the recognition that designing *with* stakeholders yields better approaches, designs, and solutions than designing *for* stakeholders. Co-design researchers recognize that everyone has expertise in their own lived experience and seek to bring that expertise directly into the co-design process. *Inclusive co-design researchers* begin even earlier in the research process to engage the expertise of diverse individuals and to better understand the needs that should be addressed by the design or research in the first place. An inclusive co-design researcher makes space at the front for other researchers or experts with relevant lived experience and provides the supports necessary to enable design *by* co-design researchers. Inclusive co-design mindset includes three aspects: **A**ppreciating, **S**caffolding, and **K**eeping. We refer to this as the ASK approach.

Appreciating: Supporting and Promoting the Role of Persons with Disabilities

An important lesson that we have learned in our many years in the field of inclusion is that people with disabilities are problem-solvers and innovators; they are challenged daily in a world that is often not designed for them and have deep understanding of the impact of design on their ability to work and play independently and with dignity.

A starting point in inclusive co-design research is appreciating the life experience and knowledge of people with disabilities. In the research process, there are several places where appreciation is expressed:

1. Seeking input from people with disabilities on what needs to be addressed by the research or the design
2. Including people with disabilities throughout the design research process to address that need
3. Compensating people with disabilities for their time and expertise at a fair rate

For many researchers and designers in co-design research, power imbalances are maintained, and the inclusive mindset is blocked by research language habits that can be hard to break. We cannot express appreciation for our co-design researchers if we continually refer to and think of them as “participants.” In our work, we refer to our co-design researchers as experts because they are experts in their lived experience. That expertise should extend to helping to determine the problems that should be addressed by design research. Many researchers see “co-designing from the beginning” as meaning from the start of the design research *after* they have determined the problem to be addressed. However, when we seek guidance on the issues that need to be addressed from experts with disabilities, we begin to remove traditional research roles and create an environment where knowledge and power are shared and expertise is appreciated. This uncovering of the need that should be addressed is, barring the research funding process, the *actual* beginning of the research process. Then, by including people with disabilities as colleagues in the research process, we continue to disrupt the power dynamic of traditional research and develop the inclusive mindset of inclusive co-design. We move from researchers and participants to researchers and subject matter experts.

Finally, we express appreciation of our co-design researchers by providing them with fair compensation for their time and expertise. We view fair compensation as a rate that is equivalent to that of an emerging scholar or what we would provide to subject matter experts in other fields.

In some cases, the expression of appreciation and value for the expertise of people with disabilities is equally unfamiliar for the expert. Some of our co-design researchers have expressed amazement to us that they have an equally, and possibly more important, role in the research process. Expressing our appreciation through our language as well as actions also supports scaffolding of co-design researchers as equals in the research process because it helps them to become aware of their expertise and strengths.

Scaffolding: Building Capacity and Fostering Success

Our co-design researchers often express surprise that their expertise guides the research and informs any findings. Many of our co-design researchers are unfamiliar with co-design activities and dynamics and may also be unfamiliar with the social model of disability that situates experience of disability as a problem of design rather than an individual deficit. Scaffolding is the steps taken to create an environment where the appreciated expertise can be exercised. The research space must be a place where people with disabilities can rightfully make and influence design research decisions with independence and integrity.

In application, scaffolding involves all aspects of creating a welcoming environment, particularly power dynamics and facilitation, activity design, necessary knowledge and activity implementation. The goal of scaffolding is to create an environment where co-design researchers can focus on being co-design researchers.

Keeping: Building Knowledge and Ownership

A measure of genuine co-design is the ability of people with disabilities to advocate and be active in design research. This ability is fostered when appreciation and scaffolding have been part of the process. Keeping is the outcome of effective appreciation and scaffolding and enables co-design researchers to take equal responsibility and equal ownership of the research process, meaning making and outcomes. In doing so, keeping builds competencies in inclusive design research and helps to shift power dynamics inside and outside of the research process away from the “academic researcher” to the “community researcher” or co-design researchers. The position of co-design researchers as advocates for the social, cultural, and economic contributions and needs of their communities and themselves is strengthened.

Applying the Inclusive Co-design Mindset

We have discovered many avenues for applying the inclusive design mindset in IDRC co-design research and will describe them in this section, drawing examples from our Future of Work projects at IDRC from 2020 to 2023 called Future of Work and Disability (FWD) (IDRC, 2022) and Equitable Digital Systems (EDS) (IDRC, 2023a). Our approaches are not an exhaustive list of things to think about, but what we know so far. We find that we continually learn and discover other ways to enhance appreciating, scaffolding, and keeping within co-designs as we work with new experts. As practitioners of inclusive design, we adapt our approaches as new understandings of inclusion and exclusion are learned or evolve within our local and global societies.

Appreciating in Action

Supporting and promoting the role of persons with disabilities first requires that people with disabilities are engaged in the research process, ideally with leadership roles. At IDRC, which is a research organization rather than an advocacy organization, we have developed and continually seek new relationships with diverse organizations that represent intersecting identities of people with disabilities.

Community Engagement and Leadership

Whenever possible, we develop our projects with disability advocacy organizations. Our partner organizations help us to find collaborators in their communities to co-research or take on other roles such as advisory panel. Our partners also provide guidance and perspectives that are important in the research. Through these networks and community lists that we have developed over time, we are able to work with diverse co-design researchers. For example, in the EDS project, the 10 partners met on a monthly basis to review research direction and project goals based on our learning from the intervening co-design activities as well as from other impacts, such as the COVID-19 pandemic.

In our work, diversity is broadly defined and includes factors such as culture, social networks, disability, income, immigration, race, and gender. Our team recognizes the importance of building a co-design group that interconnects diverse identities, relationships, different abilities, and social factors that shape people's lives. Including intersectional identities helps identify hidden structural barriers and supports understanding how individual experiences differ. Only intersectionality creates spaces for reflexive consideration and critical engagement that address the multiple forms of discrimination and barriers that people with disabilities experience.

Co-designer Researchers Are Experts

Researchers who want to engage co-design researchers may find that it takes conscious effort and practice to eradicate typical research power dynamics, where the researcher is the expert and all others are participants or subjects. Instead, it is the co-designer who is expert in their lived experience, and the researcher as co-designer is guided by these experts and may even take on a facilitation role rather than a contributor role. When we invite co-design researchers to work with us, we invite them as experts of their experience who will share their knowledge and insights based on these experiences. As part of the invitation, we usually provide a link to an accessible form so that co-design researchers can respond easily to our invitation. In our EDS project, we relied on our partners to gather experts from their communities, and in the process, we set parameters as a group to seek diverse perspectives within those communities and consider intersecting identities.

If you must recruit your co-design researchers directly without the help of a partner organization, then you may want to ask direct questions about experiences related to the problem that the co-design researchers will address. For example, in a project about barriers in the built environment related to sound, we asked potential co-design researchers about different ways that they may experience the acoustic environment:

> Please select any of the following that apply to you:
> ☐ I am hard of hearing.
> ☐ I find it hard to focus when there is a lot of background noise.
> ☐ I have sensitivity to noises (e.g., from ASD or PTSD).
> ☐ I am often frustrated by barriers related to sound.
> ☐ I benefit from sound amplification technologies like FM loops.
>
> Is there anything else about yourself that you would like us to know?

These questions helped us to better understand the kinds of experiences experts could bring to the co-design session, and we were able to choose a variety of perspectives for the limited spaces available when the number of interested co-design researchers exceeded our capacity.

A consideration when selecting co-design researchers can be the inclusion of support persons who also have relevant experience to share. In these cases, support persons are additional members of the research team rather than a replacement for the individual that they support.

Compensation

It is customary when working with experts to provide compensation as a way to acknowledge and value the experience and skills being shared. In our projects, we strive to provide co-design researchers with honorariums that show our appreciation and respect for their time and experience. At the very least, we match the hourly rates of graduate research assistants. More often, as good practice, we allot a significant portion of the project budget to co-design researchers and other contributors from the community so that expert compensation is $100 CAD/hour.

Co-design researchers should not be expected to share their time and expertise because they are an intended beneficiary of the project. It is important to acknowledge the co-design researchers' contribution to the accessible co-designs and their time commitment in ways that are understood by the community to be compensation; usually payment is financial, but there may be other forms of culturally appropriate compensation to provide as well or along with payment.

You may also ask the community what might be meaningful or useful to them as an additional benefit to participating. At IDRC, we typically offer co-design researchers other possible benefits, such as micro-badges that can be used in their profiles and resumes to delineate their work to others and/or workshops on related topics. For example, participants in a recent project looking at AI hiring tool barriers provided co-design researchers with an opportunity to attend a resume tips seminar.

Scaffolding in Action

Co-design researchers may be experiencing the research area, researcher status, process, and tools for the first time when joining a co-design. Plan ways that you can scaffold or enable their confident participation. Areas to address include design and implementation of the activity, background knowledge, and facilitation. Also, review and refine your approaches throughout the co-design research activities to improve accessibility or to be more inclusive.

We focus here on the design and implementation of the co-design approach or technique with the assumption that the research team will choose the method or technique for the co-design that will produce the desired outcome. We will not focus on what technique is best for your inclusive co-design but instead on how to think about ways to design the technique (and tools) so that it is inclusive. Design and implementation are interconnected aspects of the co-design, and neither can be planned in isolation of the other.

Once the research team has determined the technique that will work well to support the area of investigation, the next step is to begin planning the research activities. Accessibility and inclusion should be incorporated into planning for every aspect; it is not a separate step that occurs after all of the planning is done.

General Planning

In co-designs, the research team usually grows, starting with a few who have an initial idea and then building as diverse experts are identified and invited to collaborate. This variability means that at any point in the planning the decisions and thinking may involve some or all of the research team.

Collaboration Space

The collaboration space may be physical or an online platform. When selecting a physical space, choose a space that meets and, ideally, exceeds basic accessibility requirements. Choose a site that is easily accessed by public transit and has close parking. The site should have level access or an alternative like a ramp or lift *at the main entrance*, but there is much more to think about than this minimum access. Have assistive technologies on all computers being used for in-person collaboration. Assess the space carefully and think about how well your collaborators will be able to move, reach, see, hear, eat, and access washroom facilities. IDRC has some useful guidance on its BIG IDeA project site (IDRC, n.d.-a, b and there are many resources online for learning about accessibility of the built environment.

Mainstream video conferencing platforms have begun to incorporate accessibility features, but be sure to choose a platform that supports live captions, sign language interpretation (pinning or spotlighting), and translation if needed. These features must be available in all “rooms” that you use in your co-design sessions.

Recruitment

We begin recruitment for our co-designs by working with the team (this could include collaborating organizations, research assistants, and other co-researchers) to determine the gaps in the research team and consider how they can be filled. We may reach out to networks of disability organizations and other stakeholders. When these are new connections, it is important to contact them as early in the process as possible to build trust and receive their help in reaching out to their communities. Express to the organizations the goal for the activity and be transparent about what you want them to contribute and what benefits they and their communities can expect by collaborating so that they can quickly understand your need and determine how they can help.

Once we have determined the networks that we will use to reach out to potential co-design researchers, we prepare a plain language invitation that describes the project and the responsibilities of co-design researchers as well as the honorarium that will be provided. We are clear about how we are making the collaboration inclusive and indicate that co-researchers will be able to identify other needs that will support their participation when they apply. Our intention is to make it clear to those who read the invitation that we will address their participation needs (e.g., regular breaks, support person, support for childcare, or transportation). Our invitation will include a link to an accessible application form.

A sample application form that may be adapted to project needs is available at https://forms.office.com/r/ZZPLVffZ5R. The submission message for the form will include the date when we will respond as well as the email address for a project team contact. Once registration closes and the team has selected co-researchers from the applicants, then all of the applicants are notified about the decision and those invited to join the research team are provided with any further instructions or documents for the co-design workshop/process. We also use this email to ask again about participation support needs (see participation supports).

Mindset

All members of the project team must value their own and each other's expertise. In all contact with the co-design researchers, we reiterate the value of their lived experience and the expertise that they bring to the research team. We may provide scaffolding that supports co-design researchers in preparing for the co-design and builds confidence in their ability to contribute (see tools and techniques).

Participation Supports

Inclusion is about planning for and being prepared to meet the needs of each individual who is collaborating. When a participant is not able to participate fully, we see that as a design problem – that we have not provided the right environment, supports, or tools for that co-design researcher. As inclusive researchers, we always plan to have captions, accessible documents, and an accessible building. As a start, we ask our co-researchers to let us know how we can support their participation and suggest many options to make it more comfortable for co-researchers to ask for these supports. In our experience, co-researchers ask for:

1. General accessibility: large font, captions, descriptions for visuals, plain language, and other alternative formats

2. Dietary needs
3. Attendants, note-takers
4. Option to bring a caregiver or support person
5. Funding support for travel, dependent care, and support person

Other factors involved in supporting participation are:

- Timing
  - The activity start time should accommodate multiple time zones (if necessary) or longer travel times on accessible transit.
  - Breaks should be scheduled every 2 hours and must be adhered to no matter how engaged the co-researchers are.
  - All co-researchers should be aware that they may step out at any time, regardless of when breaks are scheduled.
  - Consider multiple sessions rather than one long session, especially if some co-researchers are joining remotely.
  - Share the agenda ahead of time so that co-researchers can plan for their needs.
  - Follow the agenda so that everyone including captioners and interpreters can plan their time. For remote meetings a prompt start is especially important for co-researchers waiting to be admitted to the room.
- Hospitality
  - Greet co-researchers warmly and set them at ease.
  - Engage in "chit chat" or have an icebreaker activity.
  - Offer refreshments for in-person activities.
  - Refreshments should meet a variety of dietary needs.
  - A quiet space or extra breakout rooms for remote activities.
- Additional information
  - Detailed guidance for transit and driving to the location.
  - Information about the space (e.g., washrooms, dog relief areas, accessible areas, other amenities).
  - Identify people who can assist/help.
- Necessary knowledge
  - Co-researchers may need support in learning a technique or understanding new terms or concepts. Guidance and training should be provided to create shared understandings and goals. Like sharing the rules and objectives when learning to play a new game.

Research Activities

There are many techniques that can be used in co-design research. The technique will be implemented using tools for gathering information, collaborating, and creating. Some ideas for techniques and tools can be found in IDRC's Inclusive Design Guide (Inclusive Design Mapping) (IDRC, n.d.-c). IDRC has a policy of open access, and all co-research activities undertaken at IDRC are shared under Creative Commons licensing (https://creativecommons.org/licenses/by/4.0/). All co-researchers are asked to sign a contributor license agreement and, for co-creation activities, a group attribution form.

Research Techniques and Tools

When choosing a technique, consider how well your co-researchers will perceive it and participate. For example, written narratives like letters and stories may feel foreign or awkward to someone who communicates with gestures or uses oral traditions. Narratives may also be difficult for individuals who prefer structure or are less practiced in creative writing. This consideration doesn't mean that you should avoid a technique but instead think about how the technique could be modified to suit other needs as well as what tools can support co-researcher needs. For example, when using narrative techniques as a way to gather and share lived experiences, we have used these modifications and tools:

- An expert notebook
  Prior to the first session, we provide all co-researchers with a notebook (as a downloadable doc, a Google doc (MIDP Evaluation), or paper formats) that provides some guiding questions and structures to help the co-researcher think about and collect their relevant experience (IDRC, 2020, 2023b). Completing the notebooks is optional, but we encourage all co-researchers to participate in this priming exercise. Alternatives to the notebook as a priming exercise are guided interviews or an online form. We also encourage co-researchers to collect or share their experiences with images, audio, or video if they are more comfortable. At the first session, co-researchers will bring their collected experiences or receive a copy of their entries in the online form.
- Flexible modes
  We ask co-researchers what mode they would like to use to create their contributions – audio, images, video, written, sign language video – and support their choice. Whatever mode that they select, we ensure that it will be accessible to all collaborators via captions, translations, transcripts, etc.
- Scaffolding
  To support co-researchers who may benefit from more guidance, we provide a few options with varying levels of structure. For example, some may benefit from guiding questions like: Who are your characters and what are they like? What is their goal? What happened or what was the challenge? What was the impact? How did they feel? How was it resolved? Others need more structure, like having the questions and some examples of how to respond (e.g., for What is the impact? We might have: Could they achieve their goal? Why or why not?). For even more structure and support in writing, we might use an online form to break the narrative task into smaller pieces with more precise questions to allow for simple responses that can be merged to create the narrative later. We also provide supported writing where a facilitator or support person helps create the narrative under the direction of the co-researcher.

- Small group collaborations
  Have co-researchers work in small groups of two to four plus the facilitator to create a space for them to share ideas and generate the desired outcome – in this case, a shared narrative. The facilitator may support or guide the process if needed. Small group collaboration has the added benefit of including multiple perspectives as well as protecting privacy by enabling creation of composite characters.
- Personalization
  Although we begin co-design research with flexible approaches, further personalization of the tools or techniques may be needed at any time. Don't hesitate to modify the planned route to meet your co-researcher's needs. In one of our co-designs, one of our co-researchers had immigrated to Canada from a Spanish-speaking country and communicated using ASL. Although they could prepare their work as an ASL video, they were confused about the research goals and intended outcomes, which had been provided in ASL and written English. We realized that there was a disconnect between this co-researcher and the rest of the research team and decided to reach out via email in Spanish to ask if they would like to work in Spanish instead. The co-researcher was really pleased to have the option, so we sent the instructions in Spanish and let them know that they could respond in Spanish, English, or ASL. The co-researcher was able to understand the research task better and provided input in written Spanish.

There are many tools that are commonly used in co-design research, such as, sticky notes, creative play, model building, manipulating objects like building blocks, and online tools like Miro boards. Identify the requirements for using any tool (e.g., researcher must be able to: see, reach, read, hear, grip, etc.) and consider alternatives to or modifications of the tool when a requirement can't be met. In some cases, you can use a digital tool like a table in a Google doc to organize ideas instead of a whiteboard or sticky notes. If you are using a digital tool, make sure that it is accessible and interoperates with assistive technology and that everyone has access to a device and necessary assistive technology. Be sure that all of your co-researchers can participate, and do not use tools or modifications that will segregate one or more co-researchers from the process.

Facilitation

Recall that the goal of scaffolding is to create an environment where co-design researchers can focus on being co-design researchers. Facilitators create this environment; they are the good hosts who work in the background. Like any host, the facilitator, tends to the needs of the co-researchers, makes everyone feel welcome, helps everyone find space to contribute or share, and adeptly resolves any problems that arise.

An important part of inclusive facilitation is helping all co-researchers engage in interactive styles that may feel new to them. The co-researchers with the guidance of the facilitator may discuss how interactions will occur and issues are resolved. Inclusive interactions require understanding the different needs of the group and helping others in the group to meet those needs as well.

> When we acknowledge that different levels of creativity exist, it becomes evident that we need to learn how to offer relevant experiences to facilitate people's expressions of creativity at all levels. This means leading, guiding, and providing scaffolds, as well as clean slates to encourage people at all levels of creativity. It is not always the case that we want to push people beyond their level of interest, passion and creativity. (Sanders & Stappers, 2008, pp. 13–14)

Co-researchers will need to be comfortable with longer pauses to allow individuals using captions or translation to "catch up" with the spoken words, enable remote co-researchers to unmute, and allow any co-researcher time to compose their response. Inclusive facilitation is crucial for an inclusive co-design activity; IDRC researchers helped to create an inclusive facilitation guide (https://ecampusontario.pressbooks.pub/onhumanlearn/chapter/inclusive-facilitation-guide/) that is openly available on Pressbooks (Humanizing Learning Project, n.d.).

Iterative Design

Iteration is not just for the products of the co-design research, but also for the co-design process. Co-design research should be adjusted as needed throughout the process. These adjustments are part of being flexible and may stem from observations but should also be from informal and formal feedback collection. At the beginning and end of a co-design session, the facilitator can check in with the researchers to learn how the co-researchers are feeling about the process, what is working, and what could be better. Reviewing the activities, tools, and processes as a group and making any needed adjustments is part of building trust and a sense of community so that all co-researchers are empowered and feel ownership in the work. At the end of co-design research activities, we recommend using a feedback form or a debriefing session to review the co-design and learn ways to improve it for next time.

Keeping in Action

Keeping refers to several aspects: keeping the co-research team engaged in the analysis and findings as well as keeping the knowledge, data, and research capacity within the community. Building knowledge and ownership begins in appreciation and scaffolding. In inclusive co-design research, the co-design researchers should be part of the phases where meaning is developed and disseminated. The importance of findings from co-design activities should be discovered and articulated by the co-design researchers in partnership with the initiating co-researcher. Full participation enables co-design researchers to have ownership over the research and power over how their contributions to knowledge are articulated, which will boost their trust in your research activities. Keeping is often overlooked in co-design research; perhaps because the focus in the field has been on co-design research methods rather than on co-design research analysis. Even Sanders and Stappers (2012), who have been leaders in co-design research practices, state, "One of the biggest challenges that you may face is that the people who analyze the data may not be the same people who will be using the results and they will have not been involved in gathering the data" (p. 197). Just as it takes time to shift from "design for" to "design with" and then "design by," it can take time to shift to a mindset of co-analysis and co-synthesis, but doing so fosters ownership of the outputs in all of the co-researchers.

Another challenge with analysis and synthesis is that they are typically the last phase of a research project and can take a great deal of time and effort. Sharing this effort within a deadline may feel impossible if it is not planned from the start of the research. In our own co-design research, we have had varied success in keeping. It has taken us time, experience, and reflection to better understand how we can fully share this part of the research process rather than seek feedback after the meaning-making has occurred. Now, we approach the analysis in the same way that we approach the co-research: co-analysis requires the same actions of appreciating and scaffolding discussed above.

Co-analysis and Synthesis

Data from co-design research can take a variety of forms; what you do with the data will be just as varied, but the goal is usually to create meaning from it. In the same way that a research method was chosen and adapted to meet the needs of co-researchers, the method for analysis must be selected and adapted to enable all of the co-researchers to derive meaning from the collected data. The care and planning to build capacity and foster success at the research phase (see scaffolding in action) are repeated for the analysis phase. We ensure that co-analysis can occur but plan it with our co-researchers from the start. Build co-analysis into the research activities so that it is a natural extension of the work done together in the co-design research phase.

An example of this approach is described in the EDS project research report (EDS Project, 2023) (EDS English Report; EDS French Report) (EDS Project, 2023a,b,c):

> [co-researchers] imagined ideal interactions with technology. Each group combined the experiences and set them within a narrative that they shared as a slideshow. The use of the imaginary acts as a contrast that brings into prominence the very "normal" things that people with disabilities do not expect – the kinds of things that people who are not disabled take for granted. Their stories were narrated, captioned, and shared online.

- Jessica Looks for Job: https://youtu.be/EVuTl2PG0O8
- Jumper Gets a Job: https://youtu.be/w_7nyT_EXlo
- Friendship Chronicles: https://youtu.be/wFXHNHVnyQ4
- Adventures in the Land of ID: https://youtu.be/Ux2Agx919GY
- A Typical Day: https://youtu.be/1analyzed1c
- Working with Accessibility Needs Normalized: https://youtu.be/4vosjCltLqA
- Riley's Day at Work: https://youtu.be/ok4GL9-n9_U

Later, the co-researchers met in their groups for three sessions to analyze their own and two other stories from *The Imaginary* using narrative analysis. The co-analysis was structured as a book club where people talk about things in the story that happen and how the story is told. These insights were collected and turned into recommendations for the final report.

For example, insights generated from *Jessica Looks for a Job* are shown here:

1. Job coaches need better training for people with disabilities.
2. The hiring/interview process needs to be more inclusive.
3. Workplace culture needs to be more open to people with disabilities.
4. Relevant technology needs to be available for employees to succeed.
5. Employers should understand specific employee needs (i.e., working from home if possible, working with family schedule, technology for text-to-speech).
6. Supports should be in place for accommodating service animals if necessary.
7. There should be safe spaces where work can be done privately.

Co-researchers expressed both an appreciation for participating in the co-analysis as well as a richer understanding of how the co-design research activities could generate recommendations and insights. When co-researchers do not participate in the co-analysis, a disconnect is created between the co-researcher and the outcomes; there can be a sense that their contributions had no impact. Co-analysis assures that the voices of co-researchers are maintained through the synthesis and development of the research outcomes and understandings. The increased ownership in the outcomes is ideal for dissemination and, more importantly, gives co-researchers agency to continue to use and extend the research for advocacy or other purposes.

Dissemination

Co-design research is meant to be “owned” by and have an impact on the co-researchers and their communities. Full participation in the research process from start to finish enables all co-researchers to engage in dissemination activities either formally through conferences and publications or informally through word of mouth, social media channels, and personal networks. It is important that all contributors are acknowledged in reports or other products of the co-research.

Conclusion

Adopting an inclusive mindset and applying the ASK approach – appreciation, scaffolding, and keeping – will enable co-design research activities that empower co-researchers and their communities. Inclusive co-research ensures that diverse perspectives and viewpoints inform the research process and outcomes. Inclusive co-design research requires a shift in power within the research process that can only be accomplished when the contributions and expertise of those impacted by the research or designs are sought out, included, and valued.

Inclusive design addresses the design of everything. The involvement and participation, from the beginning, of experts with disabilities is essential to applying this inclusive and participatory method. Often, inclusion and accessibility are viewed as treatments that occur at the end of a process, but this view leads to exclusion and usually remediation efforts that take more time and resources than if inclusion had been incorporated in the first place. Inclusion and accessibility should be part of all parts of the process. In research, this means that inclusion is incorporated into every decision, communication, and step of the research.

Co-design is not just a consultation, it is an engagement where those most impacted by the design or research should have a leading role – the audience is moved to the panel on the stage. Becoming adept and comfortable with "design by" research takes time and practice, especially for researchers trained in traditional research methods.

Inclusive co-design ensures that everyone is able to participate equitably and in the way that they are most comfortable and productive. Power within an inclusive co-design is either equitably distributed amongst all of the co-researchers or shifted to the co-researchers most impacted. Facilitators should be evaluating and adjusting the effectiveness and inclusiveness of the research activities throughout. With practice and thought, inclusive co-design research can become another familiar tool in the researcher's toolbox.

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CO-CREEMOS: A Strategy to Attend Diversity in Colombia

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Abstract

The national government of Colombia has been making important efforts to serve all students in the Colombian educational system, including those with disabilities or exceptional abilities. One of the latest advances in the modeling of Colombian public policy is Decree 1421 of 2017, which regulates, within the framework of inclusive education, educational attention to the population with disabilities. Within the framework of this policy and aligned with the UNESCO calls to strengthen the processes of adopting Open Educational Resources (OER) as a means to achieve true educational inclusion in an educational system, recognized as diverse, the Fundación Universitaria Tecnológico Comfenalco has prompted the creation of an institutional strategy called CO-CREEMOS that is presented and evaluated in this manuscript. Evaluation shows promising results in increasing of the teachers' awareness for developing inclusive practices using OER.

Keywords

OER · Cocreation · Universal Design for Learning · Curricular design by competences

Introduction

One of the fundamental pillars of the 2030 World Education Agenda, coordinated and supervised by UNESCO, and which governs its normative work, is the right to education (United Nations Organization, 2015). Specifically, the agenda defines the principle of "equality of opportunity and treatment for all people, without discrimination or exclusion," reaffirming to all countries the duty to promote equal opportunities for accessing education. Among the main provisions that governments must give is the access to higher education for all, on equal terms according to their individual capacities, and with equal quality environments in terms of the education provided.

Bearing in mind that governments are responsible for ensuring that internationally established political and legal provisions are complied with, guaranteeing access to quality education for all, and designing policies and strategies in their education systems, Colombia is making great efforts to promote inclusion.

In particular, the Colombian government has defined laws and decrees to achieve true inclusion in education. These laws and decrees touch higher education institutions, which are called upon to specify actions and strategies that allow access, permanence, and quality of education offered to populations with special constitutional protection. One of the latest advances in the modeling of Colombian public policy is Decree 1421 of 2017 (Ministry of National Education, 2017), which regulates, within the framework of inclusive education, educational attention to the population with disabilities.

The Fundación Universitaria Technológico Comfenalco (FUTCO), as an institution of higher education in Colombia, has accepted international, national, and local calls that urge to advance in the processes of inclusion in education. This institution has developed an inclusion policy that comprehensively addresses the concept of inclusion and touches on the most important institutional processes that are truly accessible and inclusive to the university community.

In this context, the CO-CREEMOS strategy was born (Baldiris et al., 2017), an institutional strategy that seeks to promote inclusive education in higher education institutions, intended to be initially implemented at the Fundación Universitaria Technológico Comfenalco. CO-CREEMOS includes the definition of an institutional model for the Co-creation of Open Educational Resources (CO-CREAR), the definition of a Collaborative Model for the Evaluation of Open Educational Resources (OER-Rubric), and the offer of technological tools that support both processes.

This strategy has managed to impact the institutional pedagogical model and, together with the policies of institutional inclusion, has managed to promote the development of methodologies and tools that impact the educational system based on the proper relationship between didactics and technology, giving value to diversity and inclusion.

The present manuscript describes the CO-CREEMOS strategy and consists of the following sections: section "A Pedagogical Model to Attend Diversity" describes the pedagogical model adopted by the Fundación Universitaria Technológico Comfenalco. Section "Adopting the UDL from the Teaching Project" explains how the principles of Universal Design for Learning (UDL) were assumed from the institutional Teaching Project. Section "CO-CREAR" presents CO-CREAR, inspired by the ADDIE models (Branch, 2009) and CO-CREARIA (Baldiris et al., 2015, 2016). Section "OER-Rubric" presents OER-RUBRIC, the OER evaluation model that was adopted in the CO-CREEMOS strategy. Section "Evaluation" describes the evaluation of CO-CREEMOS strategy. Finally, section "Conclusion and Future Work" presents the conclusion and future work.

A Pedagogical Model to Attend Diversity

The Fundación Universitaria Technológico Comfenalco adopts a constructivist pedagogical model that seeks to develop the cognitive structures of the student, where the teacher is a guide and counselor, but it is the students who build their own knowledge. This is how the pedagogical processes of the curriculum work, in order to build knowledge and develop competences within a specific learning environment. Here, the methodology applied is combined with logical elements which represent knowledge expressed in laws, postulates, rules, and the physical resources constituted by the space, equipment, educational materials, and support means, as well as the student's relations with these elements and with other people, be it other students, teachers, or administrative staff (Fundación Universitaria Tecnológico Comfenalco, 2011).

The two main instruments for the realization of the institutional pedagogical model are the Teaching Project and the Classroom Project. The Teaching Project defines in detail the particular strategy of the teacher in order to lead the students to achieve their desired educational purposes. The Classroom Project is the didactic strategy of mainstreaming the competences to be achieved with the students throughout the subjects. The art classroom project is based on the competencies, the knowledge that students acquire in the subjects, putting into play the competences acquired in real problem situations to which the student must provide solutions.

The fundamental work of the team participating in the design of the CO-CREEMOS strategy, from the pedagogical point of view, was the structural and methodological intervention of the design of the Teaching Project with the purpose of adopting the principles of Universal Design for Learning (UDL) (Meyer et al., 2014) and in this way provide teachers with a way to design a flexible curriculum for their students, specified in the Teaching Project.

On the other hand, from the technical point of view, the strategy guides teachers in a collaborative process of construction of OER that allow accessible digital educational resources to be considered as technological tools within the plan specified in the Teaching Project. These OER, when accessible, guarantee access for all students to the training process, including those with sensory disabilities.

The CO-CREEMOS strategy is the commitment of the Fundación Universitaria Technológico Comfenalco for the realization of action number 5 of the policy of institutional inclusion, “Have flexible curriculums and adapted to the particularities of students.”

Adopting the UDL from the Teaching Project

As mentioned above, The Teaching Project at the Fundación Universitaria Technológico Comfenalco defines in detail the particular strategy of the teacher to allow students to achieve the desired educational aims.

The teaching project initially consisted of the following parts:

- A presentation header for the teacher and their subject
- Presentation of the teaching project
- Teaching project justification, which revels the importance of the teaching
- Competence to be developed by the student, detailing the knowledge that is sought to be appropriated by students; the knowledge, what to do and who to be that is in accordance with the project of integral education of the institution
- The planning of weekly activities

The teaching project lacked before the intervention some elements necessary in order to achieve truly flexible curricula that address diversity in the classroom, as well of providing clear guidance to teachers on how to include OER as didactic strategies to promote inclusion. In this context, the following elements of information from the UDL to the teaching project were included:

- The profile of the course is defined considering the approach of the UDL describing the strengths, weaknesses, and preferences of the students in terms of recognition, strategy, and emotional aspects.
- Initial design of Open Educational Resources to include as didactic strategies in curricular planning. In this section, teachers are encouraged to think about the digital support they require for their subject, and in particular, about which OER could support the learning process of the students. Teachers are asked to describe the resources as well as justify their use. The OER are included in the planning as tools to support the appropriation of the knowledge defined in the definition of competences.
- Planning. In this stage, the teacher is encouraged to think about the best strategies that could achieve the educational purposes defined by the course profile, also to think about a planning that makes use of the defined OER.

  Up to this point, teachers were able to design their teaching project completely. However, there was a lack of evaluation regarding the capacity of the project to address the diversity of students for whom it is designed. Therefore, the following sections were included in the teaching project.
- Identification of potential barriers. As a space for reflection on the capacity of the teaching project to be inclusive. In light of the UDL guidelines, the teaching project was evaluated and, considering each profile, the possible barriers that the defined strategies could impose to students while accessing the learning process were registered.
- Once the barriers are identified, an analysis of the possible solutions that would eliminate these barriers could be carried out.

Once defined, the teaching project allowed teachers to be aware of the characteristics of the group of students to whom the subject was addressed, achieving a curriculum that would meet the needs of all, and also include the use of accessible OER. Henceforth, teachers were motivated to follow a process of cocreation of structured and systematic OER that would allow them to generate OER that would support the execution of the designed teaching project. This process is detailed in the next section.

CO-CREAR

CO-CREAR is inspired mainly in the models ADDIE (Branch, 2009) and CO-CREARIA (Baldiris et al., 2015; Baldiris et al., 2016), welcoming the principles of both models although personalizing a series of stages that guarantee that the resources obtained are adjusted to the needs of the Fundación Universitaria Technológico Comfenalco. These stages are the following:

- **Reflection on the diversity of the population, the institutional pedagogical model (PEI), and other institutional references**. In CO-CREAR, the reflection becomes a significant moment of the whole process. The teachers are always reflecting, always looking for how and why it is important to meet the diversity of needs of their students. Because they are aware of the need, this makes teachers also become aware of the fact that they can be part of the solution to the situation of exclusion experienced in a city such as Cartagena de Indias, where the Fundación Universitaria Technológico Comfenalco has its headquarters.
- **Initial OER design**. This stage begins in the teaching project, defining the OER that can support the achievement of the competences, and in particular of the knowledge that is intended to be appropriate for the students. However, elements of the curriculum not addressed in the defined OER are further deepened; examples would be a clear and detailed definition of their purposes, didactic strategies, sequencing, evaluation, and feedback given to the student in the OER. In a few words, the OER curriculum is defined.
- **Analysis of barriers and solutions**. Digital content also presents barriers. This moment is a supremely important moment to identify those potential barriers that building OER can present.
- **Mature design of the OER**. Given the initial design and the analysis of barriers, this is the moment when possible solutions are analyzed in order to eliminate these barriers through more appropriate didactic proposals or through the analysis of the web accessibility of the contents of the OER.
- **Development of the OER**. At this moment, with the help of software tools an accessible OER is created.
- **Evaluation of the OER**. Although this particular moment has been designated a stage, what it really represents is a set of partial evaluation milestones characterized according to the nature of the specific moment being evaluated.

OER-Rubric

OER-Rubric is an evaluation model of OER, which takes elements from existing models (Baldiris et al., 2014; Bonfante, Zapata, & Suarez, 2013; Nesbit, Belfer, & Leacock, 2005), while also, emphasizing the following matters which have not been considered or have been considered very little in the previous models:

- The model verifies the capacity of the OER to meet the diversity of potential students.
- The model offers a clear evaluation methodology for each category.
- Different categories of evaluation can be verified by different professionals.
- The actors that participate in this validation process.

Fig. 1 Actors participating in the evaluation

Figure 1 summarizes the actors involved in this coevaluation process.

Figure 2 summarizes the different evaluation rubrics defined for OER-Rubric and the moment of cocreation in which they apply. The strategy considers that the organization of rubrics is a great contribution of knowledge, those involved in the planning moment: UDL rubric, attention to diversity rubric, the rubric that supports teaching, the rubric that evaluates planning, and the rubric that determines where the contents belong; also the rubrics built for the moment of the collaborative development of the OER: accessibility and usability; and the rubrics for the moment of implementation: reusability and support for learning. Together they are the evaluation model of the strategy CO-CREEMOS, OER-Rubric.

Evaluation

SCENARIO, Training in Educational Practices in and for Diversity

The CO-CREEMOS strategy was evaluated in the context of the Training in Educational Practices In and For Diversity that took place from July to December 2017 at the Fundación Universitaria Technológico Comfenalco. The training was

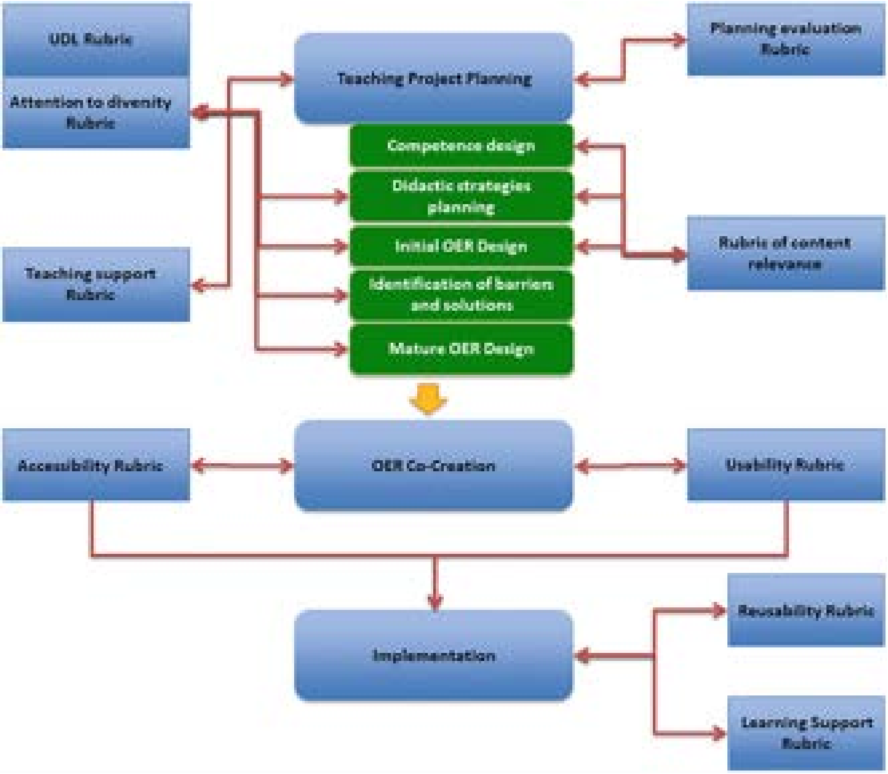

Fig. 2 OER-Rubric

offered in an open call to all the professors of the foundation. The purpose of the training was to provide teachers with concepts and tools to address diversity in the classroom, fostering the processes of cocreation of OER that meet the needs and preferences of all students. The course introduces teachers to the historical evolution of the concept of diversity, stimulating their reflection, proposes the Universal Design for Learning as the framework to be applied to address diversity, and guides the teacher in an inclusive and accessible process of collaborative creation of OER. The teacher's main challenge is to apply concepts and techniques to achieve an inclusive learning environment, in particular an Inclusive and Accessible Open Educational Resource. This resource would be one of those defined in the teaching project.

The specific competences to be acquired by the teacher are the following:

- The teacher recognizes the importance of inclusive learning for a better society.
- The teacher recognizes the diversity of the educational system and aims to propose inclusive and accessible learning scenarios considering the needs and preferences of all students.

- The teacher recognizes different conceptual models for attention to diversity in the educational context.
- The teacher plans and develops Open Educational Resources.
- The teacher applies techniques to generate accessible content for the development of the Open Educational Resource.
- The teacher evaluates the different dimensions of the Open Educational Resource developed.

The development of competences by teachers was based on the definition of an academic agenda that is presented below:

Module 1
- Epistemological framework
  - Inclusion: Historical review
  - Legal support
  - Educational perspectives at higher level

Module 2
- Methodological framework
  - Conceptual models
  - Universal Design for Learning
- Coverage in the teaching project: Competencies

Module 3
- Techniques to operationalize
  - Open Educational Resources
  - UDL guidelines by areas
  - OER design
- Coverage in the teaching project:
  - Competences to be developed by the subject (knowing, doing, being, and coexisting) and its evidences (Selecting a competence from the ones defined in the previous aspect)
  - Initial design of the didactic strategies of the OER to achieve scope of the knowledge associated with performance criteria
  - Analysis of barriers and solutions of strategies defined around the qualities of the student
  - Design of final teaching strategies
  - Programming weekly activities

Module 4
- Practical framing
  - Web accessibility
  - Mature design of the OER
  - OER Development
- Coverage in the teaching project: OER defined in the teaching project developed

Module 5

- Coevaluation
  - Conceptualization
  - Development of coevaluation

Module 6

Final presentation of the poster during a forum about OER Finally, during a pedagogical teaching induction day at the Fundación Universitaria Technológico Comfenalco, awards were given to the best experiences.

Evaluation Concept

The focus of this research corresponds to a qualitative analysis, including an analysis of discourse, which allowed to draw conclusions from heterogeneous data from a mass of textual data, from translations of interviews of participants.

From the interviews obtained from participating teachers were revised syntax, narrative form, and vocabulary used by them to obtain knowledge of some depth about their preferences, feelings, motivations, influences, and knowledge generated from the experience lived in the Training in Educational Practices In and For Diversity.

The categories of analysis in this study were of a theoretical type (Abela, 2002) and are part of the framework of the same type; they are also derived from the theory of beliefs proposed by Lewis and Passa (1998).

Lewis and Passa (1998) point out that the elements that generate beliefs are based on the organization of culture, corporate orientation, and priority in program planning. These authors consider that beliefs emanate from four circumstances:

- Reason, knowledge: Belief always supposes an element of intellectual knowledge.
- The feeling, the desire: The belief responds not only to knowledge, but also to a coexistence, to a need.
- The influence of society and environmental culture: The belief is reached from an internal driver, but, in fact, this would not be the case without the mediation of social culture, with its functions of inculturation and acculturation of the individuals.
- The individual's own will to believe: The individual is highly influenced but is never the total toy of environmental forces (Quintana, 2001). These circumstances allow us to suppose that a belief is partly intuitive, personal, and variable; intuitive because it is guided by the conjunction of rational knowledge and both rational and irrational elements; personal, because although it can occur within a given social group, it is the man himself who ultimately decides its process, settlement, change, or rejection, hence its variability according to Kleine and Smith (1987).

According to Fressier (Fressler, 1985), the individual disposition of the teacher, the organizational regulation, the management styles, the social expectations, and the professional organization determine all those phases of the life cycle of the university teacher, influencing in some way the construction of beliefs. The model includes two components, one cognitive and the other perceptual (Soto, Lacoste, Pepenfuss, & Gutiérrez, 1997).

Having a belief means that you have a truth that activates actions, both positive or negative. The term belief has the tendency to influence the individual in the generation of thought, opinions, aptitudes, and attitudes.

Participants

During the evaluation process, 24 professors from the Fundación Universitaria Tecnológico Comfenalco participated, but only 10 successfully completed the process, since many did not have enough time to attend the face-to-face meetings and b-learning mode, or to create and validate their educational resources in real classroom settings. Participating teachers submitted an initial survey, the results of which are listed below.

Initially, it is highlighted that there was a balanced participation of the female and male teaching population, as well as from various areas of knowledge: engineering, social and human sciences, administrative sciences, exact sciences, and others related to education; it is added that 75% of the participating teachers in this pedagogical and research experience have undergraduate or equivalent training, followed by 29.17% at an informal learning level, and in a lesser proportion, teachers who have performed at the secondary and primary school levels. All the teachers had more than 5 years of teaching experience.

When inquiring about their experience in the use of ICT, 8.3% stated that they had some type of economic limitation. Around 70% of the teachers consider themselves users with an intermediate level of knowledge of computers and the Internet; the rest considered themselves at an expert level.

Among the participants, 54.2% had experience with the design of Educational Resources, such as OVAs, Educational Resources, Video tutorials, Infographics, Ebook, and Programmatic Content Script, among others. Of them, 16, 7% claim to have published them on YouTube. Those who have developed OER mentioned that their resources have some type of license, showing that they are of the Creative commons Attribution NonCommercial NoDerivatives type, and around 20% of the teachers created educational resources with multiple and flexible presentation methods, expression methods, and action, as well as options for student engagement (Meyer et al., 2014).

Most teachers identify and recognize the concept of accessibility, identifying aspects such as “equal access for all, regardless of the disability that an individual has” or “giving the possibility of access to knowledge to all students, even those who have difficulties to learn” ; however, when asked about the inclusion of accessibility aspects in the development of educational resources, only 45.8% mentioned doing so, including aspects such as simple user interfaces, effortlessness and simplicity, and freedom of use.

Additionally, it was asked about the authoring tools used to create the resources, revealing that 79.2% had not used any, and those who used them used Photoshop, Fireworks, and eXeLearning. About the use of methodologies in the design process for OER creation, it was found that 50% of the participants said they used some type; however, when asking about which they used, they revealed tasks defined by themselves for the construction of the OER; the only Identified Methodology was ADDIE.

Instruments

The instrument used in the research was an interview that included the 10 following questions:

1. Professor, on a personal level, how did you perceive the course that was offered? Do you think it makes sense to address the issue of inclusion in higher education?
2. Teacher, on a personal level, what do you think were the main contributions of the course to your practice as a teacher? How did it help you improve?
3. What do you think of the modification that was made in the project to the teaching project? Do you think it is positive or negative? Why?
4. Do you think that considering the principles of Universal Design for learning as a framework for attention to diversity is a good or bad idea to apply in the university? Why?
5. Is the process of creating accessible Open Educational Resources followed adequate? Did you find it good, bad? Why?
6. Do you think that the process of creating accessible Open Educational Resources followed in the course can be carried out by any teacher? Why?
7. How do you feel about the Open Educational Resource you built? Are you satisfied? Did you achieve your goal? Why? What would be the next step for you regarding the resource?
8. Do you think that Open Educational Resources can facilitate inclusion processes?
9. What did you think of ATutor?
10. What aspects of the course would you improve? What issues do you think remained pending?

These questions were designed with the purpose of identifying the teacher's beliefs about the process that was carried out in the Training in Educational Practices In and For Diversity, which included the adaptation of the Teacher Project based on the guidelines of the Universal Design for Learning, the Methodology of

Co-Creation of Accessible Learning Educational Resources, and the use of other tools such as Atutor.

This instrument was applied to the participants, collecting qualitative information, and performing the analyzes on these data.

Method

The analysis method of the available texts from the interviews was divided into two phases, as described below.

First Phase

The units of analysis or registration were extracted for a first interpretation, for each textual expression on the 10 questions announced in numeral 2, which constitute the context unit in this work.

The assumptions made by each participant for each question were placed with relevance within a content registration matrix, compared to the theoretical aspects of Lewis and Passa's (1998) proposal on beliefs, in an interpretive exercise of recognition of their expressions around reasoning, desires, and extrinsic motivations related to their cultural environment and their personal worth on which they were projected in the learning environment recreated in the Training in Educational Practices In and For Diversity.

The result of this process is presented in the excel table hosted at the following address: https://n9.cl/tepjf in detail; their responses are categorized according to the above.

Second Phase

The interpretations identified in each of the categories were analyzed by two thematic experts in order to identify coincidences and differences, which allowed to establish solid conclusions regarding the experience of the interviewees in the Training in Educational Practices In and For Diversity.

These appraisals were subsequently reconciled among the thematic experts, allowing the identification of interesting aspects, which allowed them to identify their perception regarding the lived experience, taking into account their beliefs; this process is exposed in the excel file hosted at: https://n9.cl/pzt9e

Results and Discussion

Carrying out the analysis by the experts to the teachers' appreciations in the interview designed to find out how their experience had been in the Training in Educational Practices In and For Diversity, it was possible to obtain the conclusions presented in Tables 1, 2, and 3.

Table 1 Believe model

Category	Description
Reason	They recognize the concept of inclusion, the relevance it has in education, they recognize methodologies and strategies aimed at that goal
Feeling and desire	A great sensitivity is awakened among the participants, recognizing mental biases on the conception of disability, motivating them to generate inclusive spaces
Cultural and social influence	They recognize the need to train to handle differences in class, strengthen aspects from didactics and methodology, which allow breaking barriers and generating quality education
Will to believe	The participants see the adoption of the inclusive approach as pertinent in higher education; they propose changes at the curricular level and, going further, propose a reform in the training spaces

Table 2 Analysis of question 1

Reason	Feeling and desire	Cultural and social influence	Will to believe
They recognize the concept of inclusion, the relevance it has in education; they recognize methodologies and strategies aimed at that goal	A great sensitivity is awakened among the participants, recognizing mental biases on the conception of disability, motivating them to generate inclusive spaces	They recognize the need to train to handle differences in class, strengthen aspects from didactics and methodology, which allow breaking barriers and generating quality education	The participants see the adoption of the inclusive approach as pertinent in higher education; they propose changes at the curricular level and, going further, a reform in the training spaces

Tables 2, 3, 4, 5, 6, 7, 8, 9, 10 and 11 show the conclusions obtained from the analysis of teachers' answers to questions 1–10, considering their reasons, feelings, cultural and social influence, and willingness to believe.

Table 1 shows the description of the analysis categories mentioned above.

The next tables show the results according to teachers' response to each question.

1. Professor, on a personal level, how did you perceive the course that was offered? Do you think it makes sense to address the issue of inclusion in higher education?
2. Teacher, on a personal level, what do you think were the main contributions of the course to your practice as a teacher? How did it help you improve?
3. What do you think about the modifications that were made to the teaching project? Do you think it is positive or negative? Why?
4. Do you think that considering the principles of Universal Design for learning as a framework for attention to diversity is a good or bad idea to apply in the university? Why?

Table 3 Analysis of question 2

Reason	Feeling and desire	Cultural and social influence	Will to believe
They recognize having learned concepts such as inclusion, disability, and diversity and have appropriated methodologies and didactics that enrich their inclusive pedagogical practices, identifying barriers to handle the different needs that mark true inclusion	They recognize that the methodological and didactic contribution were significant for both the students and the teacher; this made them aware of their denial, cancellation and lack of consideration for the conditions of disability in their students, they denote a transformation that leads them to think about the needs of the students, their limitations, and especially what they must change in order to ensure true inclusion	A paradigm shift is evident with the creation of an inclusive learning environment. Additionally, they learned to support each other and work as a team independent of their disciplinary expertise, in the ICT environment "from these responses it is possible to see how they recognize their context, the way they used to lead teaching processes, and how they are influenced by the context of inclusion They are able to identify differences not only physical, but also cognitive	The participants evidenced a change of mentality, orienting their teaching practice to improve their technological skills; they recognize the value of ICT tools and resources to improve their teaching action; and in addition, they recognize their change of thought to assume it from the design, management, and evaluation

5. Is the process of creating accessible Open Educational Resources adequate? Did you find it good, bad? Why?
6. Do you think that the process of creating accessible Open Educational Resources followed in the course can be carried out by any teacher? Why?
7. Do you think that Open Educational Resources may facilitate inclusion processes?
8. What aspects of the course would improve? What issues do you think remained pending?

Table 2 shows the conclusions obtained from the analysis of question 7, which corresponds to the perception and projection of the teachers.

9. How do you feel about the Open Educational Resource you built? Are you satisfied? Did you achieve your goal? Why? What would be the next step for you about the resource?
10. What do you think about ATutor?

Table 4 Analysis of question 3

Reason	Feeling and desire	Cultural and social influence	Will to believe
Positive perception, consistent with the PEI statements, regarding the institutional model and inclusive policy of FUTCO. They are based on the UDL, allowing understanding the students' needs and the inclusion of strategies to meet their necessities	Among the participants, there is the feeling that an excellent job has been done in the adaptation, but that it is necessary to take it to the practical stage, being able to include everyone, represents a new challenge, and they recognize the effort it represents. It gives high importance to the necessary and urgent changes in the teaching project to achieve the desired inclusion of people with disabilities. Generate changes in the design, management, and evaluation of teaching activities	There is total clarity of government guidelines on inclusion. The inclusive didactic specificity is necessary in the teaching project; this improves all the planning of the teaching action and is aligned with the inclusive policy of the government	The security that this adaptation is a good reference is highlighted, that actions must be taken to make it possible from the practical point of view. Inclusive didactics and the institutional teaching project were strengthened

Table 5 Analysis of question 4

Reason	Feeling and desire	Cultural and social influence	Will to believe
They rescue aspects that are strengthened from the UDL, including planning, learning styles, and strategies to meet needs Strengthening the curriculum by competencies proposed by the institution, regarding the consideration of identifying the student's profile, and from there designing the educational action of the teaching project	They manifest the imbalance between knowledge and experience; the value of identifying people with disabilities to improve educational action in the teaching project is appreciated	The MEN demands educational inclusion, reflecting the alignment of inclusive university policy with this government mandate. The use of inclusive didactics with the implementation of new formats for diversity in disabilities is a binding element, reflected in the improvement of the teaching project	The UDL is a tool that facilitates the teaching-learning process. The UDL goes beyond academics and enables the development of a curriculum from which the needs of people are considered

Table 6 Analysis of question 5

Reason	Feeling and desire	Cultural and social influence	Will to believe
The process disassembles the theoretical from the technological support and allows the definition of clear strategies for the creation of OER	Supporting the educational process in technology facilitates it, makes it friendly, and motivates students to participate. Learning how to use technological tools for OER production was a gain. They see an opportunity to approach students in a different way, and to learn about the experience of others	Diversity has no limits for those who develop OER and for those who use them, paying attention to their needs and improving their educational processes. A change of thought, of didactic paradigm, was achieved with the use of tools for the production of OER	The need to continue training in the use of technological tools for OER production. They value the approach of the course, achieving a balance between knowledge and experience It is a collaborative construction process that must be strengthened institutionally in order to be able to implement it

Table 7 Analysis of question 6

Reason	Feeling and desire	Cultural and social influence	Will to believe
The potential of the UDL to include everyone without distinctions of any kind is valued; it gives everyone opportunities in a framework of equality. It is a process that must consider pedagogical, didactic, and conceptual-based aspects, to enable inclusion	It denotes the intention to put educational hegemony aside, and it begins to consider the heterogeneity of the student body; therefore, it values the potential of the UDL learn to recognize differences, and to guarantee everyone what they deserve	Any teacher with a certain dedication of time and minimal skills (technological and pedagogical) can understand the UDL and produce the OER	The use of the UDL would be the ideal to ensure learning There is a conviction that this process will facilitate the construction of OER, regardless of the discipline, and that this will help to develop inclusive teaching-learning processes in a framework of equality

This analysis has made possible to identify the benefits, barriers, and seriousness perceived by the participants in the course:

- Perceived benefits:
  - OER are an alternative to transform education, achieve inclusion.
  - Check the potential of OER to improve learning due to its accessibility for the benefit of the diverse educational population.
  - Learning related to the recognition of difference in terms of diversity through the definition of profiles, to generate educational processes and, above all, inclusive educational events.

Table 8 Analysis of question 8

Reason	Feeling and desire	Cultural and social influence	Will to believe
Value the inclusive potential of OER, as tools (review the use of the term; I think it is not correct) to improve learning; they are accessible, inclusive, and easy to understand OER guarantees meaningful learning, accessibility, and inclusion. They are accessible to all regardless of their limitations	The OER are an option to improve and facilitate learning in the framework of inclusive education. Teachers indicated that they believe in OER as an alternative to transform education to make it more inclusive	OER are consistent with the policy of education for all The limitations of the population are real, as are the policies that seek to promote the right to education for all, and that is why IES must guarantee these rights	Strengthens the training process

Table 9 Analysis of question 10

Reason	Feeling and desire	Cultural and social influence	Will to believe
The need to base and conceptualize pedagogically and didactically the use of technology to support the disciplinary training process is recognized They highlight the importance of supporting these spaces from both the pedagogical and technological components	The satisfaction of the teachers is clear in terms of the structure of the course and the relevance of the topics; however, they show how dedication time becomes a problem, thinking about implementing and maintaining this kind of strategies, as a guarantee of the success of this initiative and its sustainability. It is recommended to assign and respect certain times to receive this kind of training for the benefit of the process in each academic program As well as the adaptation of existing technological platforms for the parameterization of REA. A point to highlight refers to the power to contextualize the course in the university environment	It is recommended to strengthen the feedback in these training initiatives to all the teaching staff; for this, it would be appropriate to generate a reengineering process to the experience, also linking structural elements foreseen in world educational policies	The teachers created good expectations regarding the learning acquired and the development of competencies in the use of the A-Tutor platform; they also recognize their weaknesses and propose to continue with the training for the creation of OER resources, with the implementation of an institutional platform for that purpose; they recognize the importance of giving continuity to these processes, assigning the times required for the development of these initiatives, strengthening the theoretical aspects, and taking them to the practical scenario through planning, in order to measure the results

Table 10 Analysis of question 7

Perception	To improve
It denotes personal and professional satisfaction with what has been learned and achieved in the production of the OER; however, the need to make this a habit is reflected. His position is critical, he self-reflects on his experience and learning and sets himself new challenges	It is evident that they began a transformation process; they are aware that they have much to do, such as improving the resource, promoting its use, and continuing to work on the creation of OER. They recognize the potential of the UDL for the production of OER; new challenges arise for the use of tools and production of technological resources to improve their teaching performance

Table 11 Analysis of question 9

Positive	To improve
They consider that the Atutor is a fairly complete, friendly, and intuitive tool, easy to use; for this reason, they were able to overcome their weaknesses in handling web tools to support the didactic work	More training is needed to develop skills in the management of platforms to support the online teaching and learning process. They recommend improving the interface; they consider that at a functional level it complies

- Perceived barriers seen as opportunities:
  - More training is needed to develop skills in the management of platforms to support the teaching and learning process.
  - It is recommended to improve the interface of the A-TUTOR platform.
  - It is necessary to respect certain times to receive this type of training for the benefit of the training process.

- Perceived seriousness
  - Personal and professional satisfaction with what has been learned and achieved in the production of the OER.
  - The coherence and relevance of the course with the universal policy of an education for all and with all.

Conclusion and Future Work

The CO-CREEMOS strategy provides a conceptual framework supported by Information and Communication Technologies for the attention to diversity in the classroom, both virtual and face-to-face. It offers the Fundación Universitaria Technológico Comfenalco: (1) a new vision of the institutional teaching project as a curricular design instrument that welcomes diversity through the adoption of the UDL, (2) a methodological process for the development of Open Educational Resources as well as its integration in the curricular design, (4) process evaluation and associated products rubrics, and (5) technological tools to support teachers in the process of adopting the OER as a way to promote educational inclusion.

From the process of evaluation of the CO-CREEMOS strategy, a great variety of ideas have been obtained: (1) the need to favor reflection on a truly inclusive practice in the faculty it was reaffirmed; (2) the value of the Universal Learning Design is recognized as an approach and set of tools that allows the teacher to develop and implement flexible methodologies to accommodate diversity in their classroom, increasing the learning possibilities of all, contributing to education of all and for all; (3) evidence of the need to offer teachers methodologies for the development of OER that really address diversity while being truly inclusive and accessible; and (4) there is a clear need to offer teachers frameworks for the coevaluation of their educational practices.

It is important, and it is recommended to all professors of the Fundación Universitaria Technológico Comfenalco or other higher education institutions to start these curricular and didactic challenges supported by technology. They should conceptualize, escalate in the changes and visions of human thought, given that thanks to this, today the intentions in the classrooms are inclusive, and accept and respect physical, cognitive, and sensory diversity.

All that was stated above encourages teachers to conduct a research exercise in the classroom, with the purpose of knowing the potential of the student as well as their interests. They should nourish the profile of the course, the process of attention to the diversity of needs through the teaching project, and also the process of adopting OER and mature in these open practices. This exercise will inevitably lead to having clear elements that can be evaluated to validate the CO-CREEMOS strategy in an integral manner.

In conclusion, the CO-CREEMOS strategy leaves an architecture as a cocreational process, defined by clear moments, procedures, and instruments that demonstrate the knowledge management carried out. It is noteworthy that the experience was enriching in learning and feelings, generating interesting interactions at an academic level.

The following steps in the development of the CO-CREEMOS strategy will be aimed at reviewing the entire strategy in light of the UDL, the cocreation processes as well as the coevaluation, as fundamental components of the commitment to overcome the barriers that may exist in the teaching-learning process. The strategy will be further nurtured with the feedback of academic peers; this will be done in order to refine it, strengthen it, and extend its benefits.

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Recommendations to Production and Sharing of Open Educational Resources with Accessibility: The ProEDU Experience

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Contents

Abstract

ProEDU is a repository with the purpose of providing Educational Resources for students, teachers and managers of the Brazilian Network of Professional, Scientific and Technological Education. With the evidence of the lack of Educational Resources with accessibility so that people with disabilities could have access to the contents deposited in the repository, an effort was started to research the process of production of Open Educational Resources with accessibility. This work presents the result achieved over these 8 years of project bringing

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information about the Recommendation for the Production of Open Educational Resources with Accessibility, a technical document with guidelines on how to produce educational content with accessibility for People with Disabilities within the scope of the Professional, Scientific and Technological Education Network (PSTEN) of Brazil.

Introduction

In a systematic review of the literature carried out by the authors in the Capes Journals Portal databases on the topic Open Educational Resources with Accessibility (OER), no results were found with information on technical guidelines for the production and sharing of OER with accessibility for People with Disabilities (PwD) and who met technical-scientific quality criteria.

In order to promote barrier-free access to content, the planning and production of OER must incorporate technologies that consider content accessibility. It is also understood as necessary to share educational projects with the respective OER, in the repositories, including the knowledge about the planning and objectives, target audience, contexts, and prerequisites for remixing or adapting educational resources and their contents of in order to maintain methodological theoretical coherence. As a result, we present the effort made in the ProEDU project (proedu.rnp.br), a repository focused on the Professional, Scientific and Technological Education Network (PSTEN), which provides guidelines for the production and sharing of OER with accessibility for People with Disabilities.

Regarding the design of OER with accessibility, a series of Brazilian and international standards and recommendations were compiled in a document called Technical Recommendation for the Production of Open Educational Resources with Accessibility. This document presents parameters to be considered in the production process to promote the breakdown of barriers to OER content.

The production of quality educational resources with accessibility has a high cost considering both those developed by teachers and content production teams. Considering these aspects, it is recommended to adopt the philosophy of Open Education and to value the reuse of OER and the interoperability between different platforms. From another perspective, there is an enormous potential in the production of educational resources in Universities and Federal Institutes geographically dispersed throughout the Brazilian territory. It is not unreasonable to assume that many of these resources are developed with similar learning goals, representing an unnecessary technical, intellectual, and financial effort.

In this scenario, aiming to create a sharing culture, breaking barriers in accessing digital educational content, reuse, and collaborative work, ProEDU implements the flow for publishing Open Educational Resources with Accessibility considering different alternative formats or versions including the source code and the educational project that gave rise to the development of the resource.

Therefore, the objective of this chapter is to present the process and the respective flow for the production of Open Educational Resources with Accessibility from analysis to evaluation by real users. However, before doing a brief presentation of the concepts of open access and open education, passing through the concept of OER, a historical description of the ProEDU project (proedu.rnp.br) culminating in the model adopted by the project is summarized in the document called Technical Recommendation on Accessibility for OER Production.[1]

Open Access and Open Education

ProEDU's relationship with the philosophy of Open Access (Open Access) is presented in two perspectives: from the great influence of movements in favor of Open Access for the creation and dissemination of repositories; and through Open Education, a term popularized from the 1970s onwards, but currently adopted and disseminated (although not exclusively) by the OER movement (Santana et al., 2012). In this way, the understanding proposed by Amiel and Zancaro (2015, p. 919) is adopted when declaring:

> Of particular relevance to the concept of 'openness' is its articulation in various spheres of action, complementary to education, such as open science, open data and Free/Libre and Open Source Software (FLOSS), which are part of an area pulsating with activism in non-formal spaces that increasingly involve formal educational institutions.

With the understanding that Open Access is part of a strategy adopted since the development phase of ProEDU, including the modeling and definition of repository requirements, some historical and conceptual information that served as a basis for the adoption, development and implementation are presented. of computational resources and recommendations that make ProEDU a Repository of Open Educational Resources for the Brazilian Professional, Scientific and Technological Education Network.

Open Access Movement

In the late 1990s, some manifestos, conventions, and declarations claiming open access to scientific publications were registered. Such claim occurred due to the high costs imposed by the publishing market, corroborated by the increased rigidity of legislation regarding intellectual property (Shintaku & Sales, 2019). This led to the engagement of professionals involved in scientific communication, giving rise to movements in defense of open access.

In a more classic view, presented by Lynch (2003, p. 9, our translation): "Open access is a cost-effective way to disseminate and use information. It is an alternative to the traditional subscription-based publishing model made possible by new digital

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[1] Document available at http://proedu.rnp.br/handle/123456789/1648

technologies and networked communications." The National Academies of Sciences, Engineering, and Medicine (2018, p. 196, our translation) proposes a more contemporary and detailed definition:

> **Open Access**: an ambitious goal aimed at ensuring the availability and usability of academic publications. Free availability on the public internet, allowing any user to read, download, copy, distribute, print, search or link to the full texts of these articles, track them for indexing, pass them as data to software or use them for any other legal purpose, without financial, legal or technical barriers that are not inseparable from Internet access.

Thus, the strengthening of initiatives aimed at promoting free access to scientific information occurred through the constitution of this international movement – MAA – which provided for the adoption of common strategies by the community involved with the generation (research) and communication of science, aiming to make available the world scientific production in open access (Costa & Leite, 2017). According to Santana et al. (2012), definitions of Open Access were presented in three declarations, known as BBB definitions of open access: that of Budapest (2002); Bethesda (2003); and Berlin (2003). Costa and Leite (2017) emphasize, however, that even though it was not the first to coin the term Open Access, the Budapest Open Access Initiative (BOAI) "[. . .] was the first initiative to discuss the central idea of open access" (Costa & Leite, 2017, p. 46). The authors highlight three precursor documents, all from the year 1999, which served as a subsidy to the MAA's conceptions: the Declaration of Santo Domingo; the Declaration on the Science and Use of Scientific Knowledge; and the Science Agenda.

From this perspective, Sebriam et al. (2017) refer to the "open movement in favor of free culture," about which they clarify:

> It is a worldview based on the freedom to use, distribute and modify cultural, scientific and technological works and works freely. The concept of open has to do with appreciation for the act of sharing and is based on the principle that the best works are made and improved collectively (Sebriam et al., 2017, p. 28).

According to these authors, the advent of the Internet as a common good, available to all of society, gave rise to: "several aspects of promoting 'open' provision [...]. The most robust of them, which gave rise to the contemporary notion of 'openness', was Free Software" (Sebriam et al., 2017, p. 28). However, this philosophy based on sharing and collaborative construction, which is configured as the "contemporary notion of openness," as the authors point out, went beyond free software and started to involve specific themes, including Open Education (Iniciative..., 2020, electronic document; Amiel, 2012; Sebriam et al., 2017).

It is possible to see that the "contemporary notion of openness" has been expanding its reach in several sectors of the digital society. Although there are movements with this philosophy not mentioned here, it is considered more appropriate, at this time, to deepen the topic of Open Education a little, due to its connection to OER and to digital educational repositories – used to expand access and enable the right to education advocated by this movement.

Open Educational Resources (OER)

Butcher et al. (2015) summarily define educational resources as any material developed for the purpose of teaching and learning. However, Mallmann and Nobre (2015, p. 623) emphasize that: “One of the conditions for a resource to be considered educational is that it becomes a conditioning and structuring element of the teaching-learning process.” Thus, they argue that an educational resource is: “[...] an organized, intentional, systematic and formal teaching material to support the teaching-learning process.” (Mallmann & Nobre, 2015, p. 624). However, Camilleri et al. (2014) clarify that there are still tensions about what constitutes an educational resource. These are related to the nature (only digital x or not) and origin (only that produced with an explicit educational objective x any resource with potential for learning) of the resources.

In this area, there is a need for clarification on the terminology adopted, as well as on the justification for the option made. For this purpose, item 2.4 presents some fundamental questions for understanding the concept of OER, as well as its historical and terminological evolution.

Although the sharing of educational content is nothing new, there has been an increase in breadth, agility, and ease of dissemination in recent decades. This is due to the possibility of producing digital content and the greater reach of the Internet (D’antoni & Savage, 2009). This theme, according to Wiley (2002), started to be part of educational guidelines more frequently from 1994, when Wayne Hodgins coined the term learning objects. Wiley (2002) also discusses the proliferation of definitions and terminological variations used since then to describe these small instructional components.

However, it is noteworthy that the formative path of the concepts to be explored in this topic – learning objects, open content, and open educational resources – brought distinctive elements to their conceptions. In this sense, Mallmann and Nobre (2015) clarify that the variations are not only terminological, but: “[...] about the formats, pedagogical principles and the role of resources/materials/objects destined to the teaching and learning process.” (Mallmann & Nobre, 2015, p. 4).

Andreia Inamorato dos Santos, in her work on OER published by UNESCO and Cetic.br, declares: “Open educational resources (OER) are often called learning objects or open content.” (Santos, 2013, p. 21). However, the author soon establishes the distinctions between the terms, starting by returning to the concept presented by Wiley (2002) about learning object (LO): “[...] small instructional component that can be reused in different learning contexts.” (Santos, 2013, p. 21). The term comes from the field of curriculum development and instructional design, especially aimed at those courses and materials supported by technologies, aiming to promote learning from small reusable instructional blocks (Wiley, 2002; Mallmann & Nobre, 2015). However, for these instructional blocks to be considered OA and used in different learning contexts, they need to present the attributes listed by Mendes et al. (2007) and complemented by Aguiar and Flôres, namely reusability, adaptability, granularity, accessibility, durability, interoperability, and metadata.

Aguiar and Flôres (2014) add an important reservation made by Wiley (2002) by emphasizing, in addition to the essential attributes to be considered an LO, an essential characteristic – intentionality – concerning the teaching-learning process. Thus, according to the authors, Wiley assumes:

> [...] a critical position regarding the profusion of digital resources that have been referred to as "learning objects", but which serve only to glorify online teaching, in the same way that decorative figures are often used, unintentionally, to decorate school newspapers. (Aguiar & Flôres, 2014, p. 13).

In this way, it is possible to see that the importance of the essential attributes of LOs is due to the expansion of the possibilities for a given object to be reused. However, intentionality is what differentiates any digital resource from a learning object.

Adhering to the principles of the free and open source software movement (FOSS), Wiley created in 1998 the concept of open content (open content) and the Open Content License and Open Publication License. It defines open content as any intellectual work (except software) licensed to allow its free and perpetual use to carry out the activities covered by the five rights (5R) (Wiley, 2019; Santos, 2013; Costa, 2014). This definition goes back to the possibility of using these "[...] educational content open in different contexts by different teachers and students and migrating through different contexts." (Santos, 2013, p. 21).

Thus, it can be seen that when the term OA was proposed (1994), the essential characteristic elements were, in short: purpose of supporting learning (intentionality); and possibility of division/regrouping in instruction blocks aiming its reuse in different learning contexts. Wiley brought the notion of openness to educational content, establishing as a condition for a content to be considered open, in addition to free and perpetual availability, the attribution of permissions for use (5R).

Then came the OER movement, supported by two fundamental initiatives: the creation of Creative Commons licenses in 2001, which allowed greater flexibility in the face of restrictions imposed by copyright legislation; and the launch of the Open Course Ware Project in 2002 by the Massachusetts Institute of Technology (MIT) (Santos, 2013; Costa, 2014). From the last initiative came the OpenCourseWare Consortium (OCW), composed of "[...] several educational institutions around the world that have come together in a consortium to foster the OER movement through the production of content and advice on policies, promotion and research." (Santos, 2013, p. 21).

The term Open Educational Resources was used for the first time at UNESCO's Forum on the Impact of Open Courseware for Higher Education in Developing Countries in 2002, assuming the following definition: "The open provision of educational resources, enabled by technologies information and communication, for consultation, use and adaptation by a community of users for non-commercial purposes." (Forum..., 2002, p. 24, our translation). Currently, UNESCO adopts the following definition on its website:

> Open Educational Resources (OER) are teaching, learning and research materials in any medium (digital or otherwise) that reside in the public domain or have been released under an open license that allows access, use, adaptation and redistribution by third parties without cost, restrictions or limitations (UNESCO, 2019, electronic document).

Since then, UNESCO has promoted forums, conventions, and projects aimed at spreading the OER movement. An example of this is the project developed by the Institute for the Application of Information Technologies in Education, UNESCO (Institute of Information Technologies in Education – UNESCO IITE) – Open Educational Resources (OER) – whose objective is to promote the OER movement in nonspeaking countries of the English language (Badarch, 2013). The strategies defined during the meeting, promoted by the Shuttleworth Foundation and the Open Society Institute (OSI), which took place in 2007 in Cape Town, bringing together advocates of open education, also contributed to the establishment of OER (Costa, 2014). The "Cape Town Declaration for Open Education" was drafted on that occasion, based on the view that education is "built on the belief that everyone should have the freedom to use, customize, improve and redistribute educational resources without restrictions." (Cape Town Open Education Declaration, 2007, electronic document).

Thus, from the creation of Creative Commons licenses, as well as the actions developed by institutions linked to the OpenCourseWare Consortium and UNESCO to foster the OER movement, there was a majority adoption of this term to designate the materials/content/resources that include the various attributes considered essential by the aforementioned movements.

ProEDU Development History

The need to have a reference place to store and share digital educational resources produced by public institutions participating in programs carried out through the e-Tec Brasil Network (current EPCT Network) that took place in the country since 2008, by induction to Office of Vocational and Technological Education of Education Department, was required for the development of a repository to give public access to this liability of materials and courses produced within the scope of the e-Tec Brasil Network.

In 2015, the ProEDU Repository for Professional and Technological Education began being conceived as partnership between the Federal Institute of Education, Science and Technology Sul-rio-grandense – (IFSul), the Federal Institute of Education, Science and Technology of Ceará (IFCE), the Federal Institute of Education, Science and Technology of Rio Grande do Norte (IFRN), and the Federal University of Santa Catarina (UFSC), but its launch took place only in 2016 (Silva et al., 2017).

In April 2016, the first phase of the ProEDU Project began, the Repository for Professional and Technological Education, having as its main function, in general terms, to gather the various digital educational resources produced by the EPT

Network, in order to facilitate access to them and preserve the intellectual memory of the Network. In October 2016, phase 1 of ProEDU was completed, containing 400 registered OER. Phase 2 of the Project was from January 2017 to July 2018. Among its advances, the increase in the total number of published objects (which exceeded the number of 1295) and the transfer of hosting of the service to the Internet Data Center stand out of the National Research Network (RNP). The Project, currently in phase 3, started in January 2019, indicated among its priority goals the establishment of content validation and use policies, as well as the preparation of manuals for different user profiles.

The project aims to preserve intellectual memory, permanently gather in a single virtual place the production of the Professional and Technological Education Network. A key factor of the project is open access to digital educational resources to expand and facilitate the dissemination of resources in general. Based on these premises, ProEDU provides Open Educational Resources focusing on teachers, students, managers, and education professionals within the scope of Federal Institutes, in particular, and for the EPT Network as a whole. Thus, it constitutes a reference source for the institutions of the Brazilian Professional and Technological Education Network.

The educational resources made available by ProEDU meet the reusability criterion, made possible by Creative Commons licenses (Ribeiro & Catapan, 2018). They have a broad thematic classification, based on the areas of knowledge of CAPES (Brasil, 2020), and can be of 10 types, defined according to the repository communities.

ProEDU Structure and Characteristics

The content published in the ProEDU Repository is structured on two levels: the Communities – defined from the study of the media nature (types) of the files that the Repository must support – and, within each community, the Collections – established from the technological axes of the National Catalog of Technical Courses. There are currently 10 types of media: animation, audio, thematic notebook, courses, image, book, web page, digital technologies, electronic text, and video. Each community is subdivided into 17 collections that represent thematic axes: Environment and Health, Control and Industrial Processes, Educational and Social Development, e-Tec Idiomas, Management and Business, Information and Communication, Infrastructure, Military, Research in Science and Technology in Education, Research in Distance Learning/ICT, Food Production, Cultural Production and Design, Industrial Production, Professional, Natural Resources, Security, Tourism, Hospitality, and Leisure.

The second stage sought to foresee conceptual, philosophical, and technological attributes that are indispensable or desirable for the design of the repository. Through this research, experts identified 66 fields or functions needed by the repository.

Among the conceptions that guided the planning of ProEDU, the definition of policies for the production process of Accessible OER, established in the Technical

Recommendation on Accessibility for the Production of Educational Resources, stood out.

In this recommendation, there is the proposition of eight seals created by ProEDU, aimed at attesting the quality of the resources made available by the Repository and signaling the end user, in a visual and practical way, regarding the quality assessment. The seals are of three types: **Instructional Design** (ID) label – indicates that the resource has been approved by a team of experts with regard to the methodology and planning applied; **Accessibility** label (AC) – attest that the content is presented in an accessible way. It is divided into six stamps, which identify the accessibility function it has (LIBRAS, audio description, screen reader, subtitling, audio transcription, e-MAG); **Technical Scientific** label (TS) – when there is participation of experts on the subject presented in the REA, such as content writer or content reviewers.

Thus, the researches and studies carried out by the ProEDU Project work teams led to the information architecture modeling, the metadata application profile, and the resource evaluation approach that best meets the objectives and differences of the EPT Network. Among these differentials, established from the functions identified as essential to the repository during the second stage, is the availability not only of the final version of the didactic resource (with its proper use permissions informed through the assignment of flexible licenses), but also of its various instances, such as: "[...] editable source files for updating, varied formats for professional or personal printing (offset, black and white and color), lightweight versions for mobile devices (e-books)" (Ribeiro, 2017, p. 18209), in addition to the instructional project that gave rise to the resource.

This differential favors technical openness (Miao et al., 2019) because, by providing editable files from different stages of development of the resources produced by the EPT Network, it allows for its updating and adaptation, thus contributing to its virtuous circle of OER (Miao et al., 2019; Amiel & Duran, 2015). In addition, the information contained in the REA instructional project (also available in the repository) complements the description of the resource (made through the metadata) and helps to fulfill a prerequisite for the resource to be considered a learning object, the explanation of the pedagogical objective. Given the need to "[...] provide clear guidelines so that the student knows what he is expected to learn when using the learning object and the teacher (as distinct from who produced the object) knows how he could use it." (Carneiro & Silveira, 2014, p. 240).

Accessibility in Repositories and in OER

Based on universal access and the autonomy of any user to access ProEDU content, it is recommended that all OER made available through ProEDU include accessibility features for PwD, as the Brazilian Law of Inclusion (Brasil, 2015) was established on July 6, 2015, it determines in its article 27 education as "the right of people with disabilities, ensured an inclusive educational system at all levels and lifelong learning," as well as in its article 28, item II, emphasizes the responsibility of the government to improve educational systems: "aiming at guaranteeing conditions of access, permanence, participation and learning, through the provision of accessibility services and resources that eliminate barriers and promote full inclusion" (Brasil, 2015).

In addition to the right to access the content of these OERs, another fundamental point for PwD to access these contents is accessibility to the computational system that make up the repository. Accessibility to the system deals with efficient navigation from screen readers and translators from Portuguese to Brazilian Sign Language (Libras), in addition to providing contrast options, font size, and proper organization of the elements displayed on the web page, font for person with dyslexia, among others (Fig. 1). In addition, the ProEDU Repository's Technical Recommendation on Accessibility for Open Educational Resources is intended to support the adaptation of OER already produced and to provide subsidies for the planning and production of new OER.

The OER deposited in ProEDU that include the accessibility features and models proposed by this Recommendation are identified from a set of accessibility seals. Each feature or template has its own label.

Accessibility seals are awarded to OER from the completion of validation processes; such processes presuppose the participation of PwD in the accessibility assessment. The synthesis of the application of resources and models can be found in the annex of the Technical Recommendation on Accessibility for the Production of Educational Resources.

Fig. 1 Accessibility features implemented in the ProEDU interface. (Source: Prepared by the authors)

Planning and Production of Open Educational Resources with Accessibility

Considering the need to develop OER with accessibility for PwD, ProEDU mapped the production process of Educational Resources for PSTE - Professional, Scientific and Technological Education, taking into account accessibility in different types of media, as presented in the section “ProEDU Structure and Characteristics.”

With the significant increase in the use of digital educational technologies, as published in the statistical notes of the School Census carried out in 2017, ID professionals can, in the current context, turn their attention to this PwD audience.

The number of enrollments of students aged 4–17 with disabilities, pervasive developmental disorders or high skills in basic education has grown substantially in recent years, and, in addition, the percentage of students in this age group included in regular classes has increased from 85.5% in 2013 to 90.9% in 2017. Considering this same age group, the percentage of students who are in regular classes and who have access to specialized educational services (AEE) also rose, from 35.2% in 2013 to 40.1% 2017 (INEP, 2018, p. 9).

So that Virtual Learning Environments (AVA) and OER that make up courses in general are accessible to students with disabilities, it is necessary that the adaptations of these AVA and the development of these OER follow specific accessibility recommendations. Therefore, the ID model of these elements should adapt to these recommendations with regard to production flows and team composition for this purpose.

The accessible ID model that will be proposed can be applied in different teaching modalities, not being restricted to Distance Education (DE), considering that the flows will be the same, only modifying the nature of educational resources and the environment in which the instruction will occur. In future works, the ID model will be presented in a generic way, that is, applicable to other teaching modalities.

In summary, this proposal suggests the adaptation of the Extended ADDIE Model where the pilot execution phase includes the validation of accessibility of courses, among other recommendations related to flows and insertion of new professionals in the educational project team.

The process takes into account two phases (Fig. 2): design and execution. In the design phase, the flow goes through three steps. In the first step (analysis), it is necessary to consider the PwD public and their specific needs for access and understanding of the content. In the second step (design), the educational resources must be designed and a team must be provided for the production or adaptation of existing materials to implement accessibility to the contents. In the third step (development), production flows or content adaptation flows must be defined for the development of the educational project for the production of Open Educational Resources with Accessibility. In the execution phase, the first step (implementation) deals with the availability of the Accessible OER, the second step (pilot execution) aims to allow access and use of the Accessible OER, and the third step (evaluation) aims to obtain feedback from the public, especially People with Disabilities, in order to improve the Accessible OER. If so, the process is restarted.

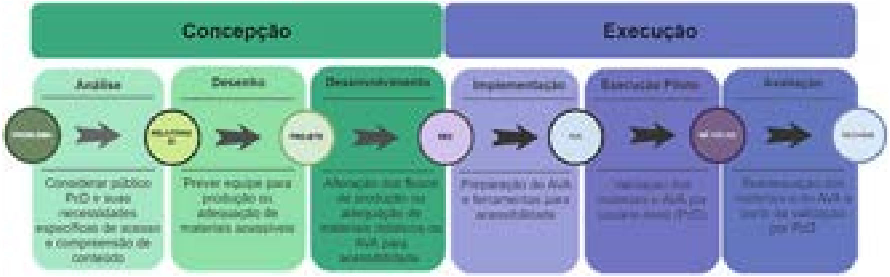

Fig. 2 Proposed instructional design template with accessibility. (Source: Silva et al. (2019, p. 747))

About the proposal, this chapter presents a synthetic model under the name of Accessible Instructional Design (AID), as a preliminary result of this research together with the proposal of team composition.

The model proposed in emerges as a result of projects that involved the insertion of accessibility routines in the production or adaptation of OER and VLE in self-instructional or tutored distance learning courses. From the pilots carried out, this model emerges as a hypothesis of Accessible Instructional Design.

Concluding the line of reasoning presented throughout this chapter, the following are presented as future perspectives: the complete development of the Accessible Instructional Design Model (AIDM) flow to support the construction of the OER project considering accessibility, as well as prerequisites for the design of accessible courses, and also the production flows or adaptation of teaching materials for commonly used educational technologies and guidance for the adaptation of an accessible VLE.

Final Considerations

Over the 5 years of the project, the lack of technical and intellectual products that deal with the production process of OER with Accessibility was evident. In this sense, an effort was started to map the process of production of educational resources, incorporating technical aspects into the flow to provide accessibility to OER. The focus of this effort was to present recommendations for production teams, especially those with Instructional Designers, to become able to break down access barriers to content and systems produced by the team or institution.

In addition to the technical recommendation for the production of OER with Accessibility, a qualification is being produced, in the distance modality, having as target audience the educational design centers of the EPT Network. This course is justified by virtue of meeting the recommendations for making content open to everyone. Providing non-excludable materials requires significant changes to the development process, from planning to final editing.

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ICT to Support Inclusive Education in the Republic of Argentina

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Contents

Abstract

UNESCO in its 2030 Agenda sets the guidelines that are needed from an educational point of view in order to equip all people with the knowledge, skills, and values that will allow them to live with dignity, build their lives themselves, and contribute to the societies in which they live. The Sustainable Development Goal No. 4 of the 2030 Agenda constitutes the synthesis of education's goals: "to guarantee an inclusive, equitable and quality education and to promote lifelong

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learning opportunities for all." Following this mandate of UNESCO, each country assumed the commitment to act toward it. This chapter describes the situation in the Argentine Republic, placing emphasis on actions related to Information and Communication Technologies (ICTs). In particular, this chapter addresses inclusive education from aspects related to disability, gender, indigenous populations, and isolated regions. First, we present Argentina's regulatory framework in relation to the aforementioned aspects. The different resources and ICT-based learning strategies that have been implemented in our country in this regard are then addressed generally. Subsequently, we describe some technological proposals that were made in Argentine universities. Finally, we identify the strengths and advantages of these technologies in relation to inclusive education in Argentina. It is our hope that this chapter will contribute to disseminating the state of affairs in Argentina in relation to its quest to achieve an inclusive education hand in hand with ICT.

Keywords

Inclusive education · Information and Communication Technologies · Argentine legislation on inclusive education · Educational applications for inclusion

Introduction

Twenty-first-century education calls for formative actions that enhance creativity and the continuous search for knowledge from all points of view and areas related to human beings. Inclusive education reflects the search for equity and equal rights among all people; thus, it arises under the conviction that the right to education is a human right and, therefore, of all people. From this perspective, when referring to inclusive education we shouldn't think only of people with disabilities, but also think of those who live in poverty and marginality, those who belong to non-majority ethnic groups, those who speak minority languages, those who live in remote areas, and those who are marginalized because of their gender. It means, therefore, focusing on all students, especially those that are most vulnerable and who tend to be excluded from the educational system. As described by Cabero Almenara and Fernández Batanero (2014), inclusion is not the same as integration, since inclusion implies moving from an individual model, where the limitation is considered to belong to the person, toward a social model where the problems and limitations belong to the society. Thus, while the main concern of integration is to change and improve Special Education, that of inclusion is to pursue the transformation of culture, educational organization, and school practice in general.

In this way, it is not possible to put aside a resource such as Information and Communication Technology (ICT), and hence the ICT-inclusive education binomial must be understood as a strategy that allows for digital resources to be brought closer to all people regardless of their status or condition from a social, psychological, cognitive, emotional, family, economic, or geographical point of view, for instance

(Yu et al., 2016). Thus, inclusive education mediated by ICTs becomes transversal to all environments of life, providing a large number of learning opportunities, the creation of educational communities, and the search for achieving the greatest number of competencies in students of all educational levels (Freire et al., 2010). Consequently, the chief purpose of ICT in the field of inclusive education, as Marín et al. (2014) indicate, pivots around the objective of achieving the development of the maximum number of capacities and abilities of individuals, in addition to promoting the participation of citizens toward the growth of society, in a large sense.

The interaction between the digital world and educational inclusion, that is, the ways in which the digital world can contribute to the development of learning environments that take into account the diversity of students, and that promote other ways of teaching and learning, and of living together and relating, as well as the commitment to educational innovation oriented toward equity are the focus of this chapter.

The chapter is organized as follows: section "Inclusive Education in Argentina" presents an overview of the legal framework in the Argentine Republic, as well as some actions taken in relation to education for people with disabilities, education for native peoples and migrants, and education for the LGBTIQ community, which is made up of lesbian, gay, bisexual, transgender, intersex, and queer people. Section "Inclusive Education and ICT" specifically addresses the use of ICTs in promoting inclusive education, reviewing technological resources (based on both general learning technologies and assistive technologies, or ATs) and ICT-based strategies to help all students achieve their full potential. This section also presents some technological developments, carried out in Argentine universities in order to support educational inclusion, especially in the universities where the authors of this chapter are affiliated. Finally, section "Conclusions" outlines our conclusions about what was done so far and what still remains to be done regarding the application of ICTs in relation to inclusive education in Argentina.

Inclusive Education in Argentina

The educational system has made significant advances in regulations that expand and consolidate the rights of students. The National Education Law No. 26206 (LEN) is the one that sets the greater objectives of education and regulates the exercise of the right to teach and learn, which is established in article 14 of the National Constitution of the Argentine Nation from 1994 and the international treaties incorporated therein. In article 11 of the LEN, which sets the aims and objectives of the national educational policy, the following is highlighted in two of its sections: "*e) Guarantee educational inclusion through universal policies and pedagogical strategies and the allocation of resources that give priority to the most disadvantaged sectors of society f) Ensure conditions of equality, respecting the differences between people without admitting gender discrimination or of any other kind.*"

The following are regulations developed in Argentina for the inclusion of people with disabilities, indigenous peoples and migrants, and the LGBTIQ community, as well as some specific actions in relation to educational inclusion.

Regulatory Framework

People with Disabilities

Argentina has extensive legislation in relation to people with disabilities. It was the first Latin American country to recognize their rights, in 1981. In 1987 the National Advisory Commission for the Integration of People with Disabilities (*Comisión Nacional Asesora para la Integración de Personas con Discapacidad* – CONAIPD) was created. Then, in 2008, it joined the United Nations Convention on the Rights of Persons with Disabilities through Law 26378; through Law 27044 of 2014, a constitutional hierarchy was granted to the Convention.

The National Disability Agency replaced CONAIPD, as of 2017, and it is now in charge of the design, coordination, and execution of public policies on disability.

Additionally, the social model of disability supported by the World Health Organization and the United Nations is proposed in Argentina. There are different regulations for specific issues about disability, including screening, treatment, digital accessibility, and work.

Access to education for people with disabilities is protected by the National Constitution, the regulations already mentioned, and the LEN No. 26378 of 2008, which maintains that the Argentine state guarantees equal opportunities and is committed to working toward the inclusion of students with disabilities in the educational system in general and universities in particular. Specifically, higher education for people with disabilities is guaranteed by Higher Education Law 24521 of 1995 and its amending Law No. 27204 of 2015, which specifies the effective implementation of state responsibility at the level of higher education. All Argentine legislation on this issue is available in the National Disability Bulletin (*Digesto Nacional de Discapacidad*).

Indigenous Peoples and Migrants

Argentina is a multicultural, multiethnic, and multilingual country, due both to the presence of indigenous populations and to migrants who speak different languages and have different cultural origins. In the country, there are 31 indigenous peoples living in different areas, who speak different languages, out of which 15 are officially recognized and 9 are in the process of "revitalization." All this generates very diverse local environments. In the 1980s, education policies related to indigenous issues began to be analyzed. In 1994, the Constitution of the Argentine Nation was amended, including article 75, paragraph 17, which "recognizes the ethnic and cultural pre-existence of the Argentine indigenous peoples" and "guarantees respect for their identity and the right to a bilingual and intercultural education."

In addition, article 52 of the LEN establishes: "Intercultural Bilingual Education (IBE) will be featured in the educational system of the levels: Initial, Primary and

Secondary Education so that it guarantees the constitutional right of indigenous peoples, in accordance with article 75 paragraph 17 of the National Constitution, to receive an education that contributes to preserving and strengthening their cultural guidelines, their language, their worldview, and their ethnic identity." Among its lines of action, there will be teacher education and training, production of materials, scholarships for indigenous students, regional agreements with Andean countries, and monitoring and evaluation of IBE experiences and programs.

In 2007 the Ministry of Education created the National Intercultural Bilingual Education Program in order to strengthen IBE actions. In 2010, IBE was ranked as "Modality" and assigned tasks and responsibilities in each one of the compulsory educational levels and in teacher training.

LGBTIQ

In Argentina, the LEN and the National Law on Comprehensive Sexual Education No. 26150 from 2006 ensure equal conditions and respect for differences, affirming the right not to be discriminated against, based on gender or any other aspect. Special mention is made of comprehensive sexual education as one that "articulates biological, psychological, social, affective and ethical aspects" with the purpose of "promoting learning based on respect for diversity and rejection of all forms of discrimination."

In 2012, Congress passed the Gender Identity Law No. 26743, which establishes the right and recognition of people's gender identity.

In 2013, the National Law No. 26892 was enacted regarding the promotion of coexistence and addressing social conflict in educational institutions, with the aim of promoting "respect and acceptance of differences, the rejection of all forms of discrimination, harassment, violence and exclusion in interactions between members of the educational community" (art. 2) as well as preventing and acting against "abuse, discrimination, bullying or any other form of violence between peers and/or between adults and children, adolescents and young people" (art. 8). According to a study on violence in education in Latin America carried out by UNESCO (2015), Argentina is the only country in the region whose legislation addressing homophobic and transphobic, gender, and school violence is considered "sufficient."

Inclusive Education in Argentine Universities

Actions for the Inclusion of People with Disabilities

In 1991 the University Network for Special Education (*Red Universitaria de Educación Especial* – RUEDES) was established, made up of programs on Special Education in public universities. It sought to generate an interuniversity space that promotes the training of human resources and research in the field of Special Education and disability. In 1994, the Interuniversity Commission on Disability and Human Rights was formed, whose primary function was to provide an area where the insertion of people with disabilities in university life would be analyzed. Later, in 2003, the Interuniversity Network for Disability and Human Rights emerged, which made it possible to incorporate more universities, consolidating the actions carried out so far. Its fundamental objective is to promote accessible universities. It tackles topics such as physical, communicational, and academic accessibility, flexible curricula, and teacher training. It seeks to incorporate the paradigm of Universal Design in the approach to disability and it is currently called the Interuniversity Disability Network. In 2007, National Interuniversity Council approved the Comprehensive Accessibility Program (Res. N° 426/07) that includes physical and academic accessibility, which includes communicational accessibility, educational equipment, and training of the different actors within the university community.

The most frequent technical aids are bibliographic materials that are adequate, computers with voice readers, screen magnifiers for students with vision impairments, enlarged photocopies, the interpretation of Argentine Sign Language (ASL), braille material, voice magnifiers, magnetic rings, voice recognition, haptic maps, talking library, and audiovisual material (Méndez & Misischia, 2019).

Regarding the academic offer of Argentine universities that favors the inclusion of people with disabilities, there is the University Diploma in Interpretation of Argentine Spanish Sign Language (TUILSA-E), which is taught at the National University of Entre Ríos. At the National University of Quilmes there is a postgraduate degree called "Production of Digital Didactic Materials with Accessibility," and at the National Technological University there is another program in "Accessibility and Web Usability." Special Education graduates are also trained at the National Universities of San Luis and San Martín.

Actions for Aboriginal Peoples

Regarding the training of human resources in IBE there are two universities that currently provide this training: The National University of Santiago del Estero (Universidad Nacional de Santiago del Estero – UNSE) offers a diploma in IBE with a mention in Quichua language and the National University of Chaco Austral teaches a bachelor's degree in Intercultural Bilingual Education. There is also non-university higher education training with an intercultural approach in different provinces of northern Argentina (Guaymás, 2018).

Considering that large groups of indigenous populations live in rural areas, having campuses close to where they live helps their members access higher education. Guaymás (2018) published a list of actions carried out in 19 public universities with the aim of working with students and indigenous communities, especially. Among them, there are classes, centers, and programs that are open and that work with students and indigenous communities (Mato, 2020).

Since 2000, the Secretariat for University Policies has included a subprogram for indigenous students within the National University Scholarship Program, achieving greater visibility for indigenous students; in some universities, it helped form support and research programs (Mato, 2020). Something else to highlight is the Indigenous Peoples Program of the National University of the Northeast. This program, the first in the country with these characteristics, has an Advisory Commission made up of representatives of the three recognized indigenous peoples in the province of Chaco (Qom, Wichi, and Moqoit). The inclusion of indigenous youth and adults within university programs is promoted through different actions, such as offering scholarships or tutorials.

Among the programs that involve ICTs and that benefited from the participation of telecom and Stanford University, is the "Programmable Open Mobile Internet," which aims to improve access to education for the most marginalized populations, encouraging reasoning, creativity, and a scientific attitude in children and young people, by using mobile technologies (smartphones/tablets). The Ministry of Education participated along with universities, technological institutes, and social organizations. In Argentina, within the framework of this project, pedagogical strategies were generated using cell phones in the provinces of Misiones and Salta. Interactive educational games where the premise is to "learn by playing" became a reality. The applied pedagogical model is based on the design-based learning approach that aims at project-based learning.

Actions for LGBTIQ

In 2012, the National Program for Comprehensive Sexual Education began in Argentina, which has trained almost 80,000 teachers throughout the country so far. Within it, it's worth mentioning there are contents that include a "critical approach and analysis of masculinity and its dominant representations: force, aggressiveness, violence" and "reflections on the implications of homophobia."

Currently, Argentina is a member of the Ibero-American Education Network LGBTI (*Red Iberoamericana de Educación* – RIE), a group of organizations that works in favor of promoting and respecting human rights for LGBTI persons in the educational field. Its main objective is to help prevent and eliminate all forms of discrimination based on sexual orientation, gender identity, or gender expression in the classrooms of Latin American countries. RIE worked to improve the school environment of LGBTI teachers and students, promoting public policies that institutionalize educational projects that take into account human rights focused on sexual and gender diversity. The Argentine LGBT Federation, the main Argentine NGO in matters of sexual and gender diversity, created in 2005 through the Ministry of Education, ensures that all people can enjoy a multicultural and inclusive education.

In the provinces of Buenos Aires and Tucumán, there are educational centers that enroll the trans and transvestite community in secondary studies: Trans Mocha Celis Secondary School and Open Doors Trans Educational Center.

Examples of Actions in Two Argentine Universities

Starting with the national regulations mentioned above, each university began issuing its own regulations and taking action toward inclusive education. As an example, there is the case of the National University of Santiago del Estero (Universidad Nacional de Santiago del Estero – UNSE) and the National University of Tucumán (Universidad Nacional de Tucumán – UNT), two public universities in northern Argentina; being institutions of the national state, they have the non-delegable function of providing access to higher education to people with disabilities under equal conditions.

In 2011, UNSE published its Institutional Declaration on Disability and created the Disability Commission, which guarantees equal opportunities for all members of the university community. Its objective is to contribute to the inclusion of people with disabilities within the university environment, developing actions that favor full integration and eliminating physical, academic, and attitudinal barriers. In 2015, the Manual of Action and Good Practices for Inclusion at UNSE was issued. It presented a set of basic actions referring to the different instances of the teaching and learning processes that ensure access, entrance, and completion for students with disabilities.

In addition to the work carried out by the Disability Commission, it is important to highlight the work carried out by the Center for Educational Pedagogical Orientation (COEP). This center works on the implementation of Universal Design, optimizing academic accessibility. With this aim, it advises on adapting the learning paths and evaluation mechanisms for students with disabilities. It provides direct assistance to students and teachers, on the one hand, and participates in the Disability Commission where it addresses general problems, on the other. Among its most important actions, the inclusive workshop for applicants to enter UNSE stands out. The main tasks and challenges of COEP in terms of inclusive education were published by Barrera Nicholson et al. (2020).

At the UNT, the Program for Disability and Social Inclusion (PRODIS) was created in 2007, as a result of a political decision by the university to achieve the full inclusion of people with disabilities, using strategies that allow the accessibility of the institution in a comprehensive way. Among the actions carried out, the following stand out: training courses in reading and writing Braille and stenography for blind or visually impaired people, computer training for people with visual and hearing disabilities, a workshop on basic computer tools for people with intellectual disabilities, and courses in Argentine Sign Language (ASL). In addition, a Department of Digitization was created, which supports a permanent communication accessibility service by adapting bibliographic material to accessible formats such as audio and Braille. This service is also provided to students from other educational institutions. To promote communication accessibility, the support of sign language interpreters is available to students who require it.

In 2017, UNT, through PRODIS, began a set of actions aimed at the entire university community. Among them are designing UNT virtual sites that comply with international accessibility standards, digitization of material that has to do with communication accessibility, and training of personnel from different levels (teachers, non-teachers, and students) in basic notions of ASL.

UNT counts with working groups that are very committed to the issue of disability in various spaces. The Department of Special Education of the Faculty of Philosophy and Letters has investigated the barriers encountered by students with disabilities in their university careers and developed teaching strategies to favor accessibility in their educational trajectory. It produced great scientific papers on the subject, some contributions being Contini et al. (2013) and Esterkind and Hormigo

(2015, 2020). Other initiatives have to do with the Universal Design Office of the Faculty of Architecture and Urbanism, which works on physical accessibility, as well as the actions and research projects by the Faculty of Exact Sciences and Technology, which are aimed at the development of technological aids and communication accessibility tools.

Within a program funded by the SPU for public universities in 2012, all students with disabilities were provided with notebooks, adapted to their needs, which was a great advance in academic and communication accessibility.

In relation to aboriginal peoples, UNT founded the Center for the Rescue and Revaluation of Cultural Heritage in 1989, which performs a scientific task at the service of their culture, starting from the multiple problems regarding identity and cultural heritage in the northern region of the country.

In 2009, the Native Peoples Department was created within the Faculty of Philosophy and Letters of the UNT. From this space, indigenous leaders teach classes, addressing different problems that affect their communities. The department works with the Union of the Peoples of the Diaguita Nation, allowing interaction between students and members of recognized indigenous communities in the provincial territory.

Inclusive Education and ICT

The use of ICTs with regard to attention to diversity implies extending the principle of educational equity. But the importance of the use of these in the field that concerns us is found both in what they can contribute to the subject (acquisition of competencies) and in the way in which they can favor the transformation of the learning context so as to offer more and better learning opportunities and development for all (García García & López Azuaga, 2012).

At this point, it is important to highlight the distinction between what was called integrative uses and inclusive uses years ago (García García & Cotrina García, 2004). The purpose of integrative uses is more focused on the compensation of inequalities from a more individualistic approach. In the second instance, that of inclusive uses, the introduction of ICTs and their use represents an opportunity to move toward a more cooperative, meaningful, and interactive education model at the service of contexts, which allows more tailored attention to needs and interests.

In this regard, an interesting line of research is starting to open which associates ICT and inclusive education. The beginnings of it are translated into studies about accessibility, which refers to the conditions that environments, products, and services must meet in order for them to be understandable, practicable, and usable by all people (Spanish Association for Standardization and Certification, 2012). This definition is the result of a line of thought in which a specific medical problem or special need is not something that should be considered by itself, but rather this sort of thinking emphasizes the diversity of all people and their situations depending on access, and believes that access should be provided to all.

However, inclusive ICT research is currently advancing along other paths, that of Universal Learning Design (UDL) (Ruiz Bel et al., 2012). UDL precisely states that disability is in the environment and points out that it is the environment that is disabling. Among the principles of Universal Design is to provide multiple means of representation to address the multiple modes of perception and understanding of what is presented for learning. ICTs can be used to support inclusion by providing different ways of presenting information, expressing knowledge, and engaging in learning, including assessment. Thus, going more in depth regarding ICTs and attention to diversity, it is relevant to review technological resources and ICT-based strategies that support all students reach their maximum development.

Resources and Strategies

When analyzing ICT-based resources, it is necessary to refer to both general learning technologies and assistive technologies designed specifically for people with disabilities (UNESCO, 2020).

Technologies for General Learning

Regarding technologies for general learning, Passey (2017) states that there are new opportunities regarding the availability of technological solutions. Three examples are indicative of the new opportunities that are now opening.

First, there are digital platforms, computer applications that allow the integrated and related execution of a series of tasks related to school administration, communicating with families, and, of course, schoolwork. Temesio Vizoso (2016) affirms that distance education through digital platforms constitutes an opportunity to give access to people who are in a situation of disability. However, in a practical sense, none of these environments is fully accessible to these people. A growing interest in digital educational resources, in general, has arisen together with digital platforms. In relation to these, IMS Global Consortium (2012) developed an accessibility proposal focused on the adaptation and customization of resources, interfaces, and content that meets individual needs. But most content is still not accessible even with standards like Web Content Accessibility Guidelines (WCAG) and IMS Global.

The second emerging technology is the interactive whiteboard. This blackboard, connected to a computer, allows easy use of interactive and multimedia resources by the teacher. The reasons for its success are fundamentally twofold. On the one hand, it is a friendly technology with traditional teaching models because it respects and reinforces the central role of the teacher and does not require a substantial change in their teaching methods while allowing them to access a greater variety of digital resources. On the other hand, its costs are relatively low, as well as its rate of obsolescence.

The latest technology, however, represents the antipode of the electronic board because it aims to universalize access to technology by making a reality the principle of each child benefitting from a computer or a tablet. Inexpensive laptops and tablets are no longer a pipe dream, and existing offerings are backed by big hardware builders. The advantage of one-to-one policies is that they make it easy for each student to have a personal device and take it home to continue working with it. However, this idea had a lukewarm reception in the school environment because justifying the investment would be possible only by intensive use.

To these three technologies proposed by Passey, a fourth group could be added that Castro Lozano (2012) calls "Support Technologies for Ubiquitous Learning" (STUL) and that includes, in addition to supporting technologies for online learning, the mobile computing devices, ubiquitous computing devices, and natural interfaces. All of them are characterized by being non-intrusive, accessible, easy to use, and adaptive. With mobile and ubiquitous computers, a new chapter to inclusive education opens, which favors communication. Some students with diverse needs have serious difficulties in social interaction, due to a deficit in communication. Fortunately, the latest technological developments, the proliferation of mobile systems, tablets with hundreds of thousands of applications, and new trends such as ubiquitous learning (UL) systems and the "Internet of things" will help increase communication skills for students with diverse needs. But to achieve normalization and school inclusion of students with diverse needs, it is vitally important that teachers, tutors, and the family of these students understand the importance of using STUL, use them, and even develop specific activities with them, adapted to each case.

Assistive Technologies

There are several different definitions of AT. The focus here is on ICTs used by people with diverse needs and/or older people "to overcome social, infrastructure and other barriers, for independent learning, full participation in education and conducting learning activities safely and easily, and with minimal assistance" (Hersh & Johnson, 2008). Students may need support and training to use AT successfully, so it is convenient to consider AT and assistance as complementary, whenever possible, and to provide resources for students to choose from.

The use of AT enables many students with diverse needs to study and do so effectively. Thus, people who need alternative ways to access systems due to differences, for example, in dexterity, reach, or mobility can use a variety of input devices, such as large keyboards, head, foot, or eye control systems, joysticks, simple switches, sipping and blowing devices, and adapted mouse switches, along with touchscreens. Blind and visually impaired people use screen readers, screen magnifying, special glasses, and, less frequently, Braille displays to access what is on the screen of many ICT devices, and some even provide access to feedback on what is being written and the operations that are carried out on the computer. Studies show that the use of AT by visually impaired students can promote expectations of success and help them develop skills (Tuwaym et al., 2018).

It has been found in a series of studies reported by Stephenson and Limbrick (2015) that the use of touchscreen mobile devices for communication and automated prompts can be very effective for people with cognitive developmental disabilities. At the same time, however, all the studies were on a very small scale.

A meta-analysis of the impact of the use of ATs (Alper & Raharinirina, 2006) found that several of them had positive impacts on literacy skills (such as improvements in writing performance and holistic quality, spelling, and grammar); other studies have found positive impacts on math skills (Wynne et al., 2016).

In agreement with Alnahdi (2014), it is possible to affirm that general-purpose technologies have advantages over ATs with respect to benefitting from greater availability, lower costs, and less stigma since they allow students with disabilities to use the same technologies as all the other students.

In conclusion, technologies should be fully accessible to students with disabilities, and all other students, as well as take into account gender, social and cultural issues, and the values and sensitivities of the diverse populations that could use them. On the other hand, the recognition of the different and sometimes conflicting needs of different groups of people with disabilities or otherwise further gives importance to the customization of learning.

Developments in Argentina

In 2018, the Second Meeting of Technologies for Inclusion was held, organized by the Ministry of Science, Technology and Productive Innovation and the National Agency for Disability. In the event, whose main objective was to make visible the capacities and contributions of people with disabilities, projects developed in the country about inclusive technology were exhibited.

Thus, for example, a customizable reading application for young people with dyslexia and intellectual disabilities became known. The main idea was to have an easily replicable application, which is the first in a collection of stories. The National Technological University (UTN) participated in this project together with other organizations related to disability.

Tactile teaching devices for the scientific literacy of blind and visually impaired people at different educational levels were also presented. This involved the design and production of innovative low-cost tactile teaching devices for teaching and learning mathematics and science in general (physics, astronomy, geography) for use in educational institutions. Among others, the National University of General Sarmiento was part of the proposal.

“Indistin@s” (Inclusion of People with Disabilities starting from Information Technology for Everyone) was also announced. The proposal included the development of an application for mobile devices that would be used as a teaching facilitator for teachers of Natural Sciences in schools with students with hearing disabilities. Among other organizations, the Faculty of Exact and Natural Sciences of the University of Buenos Aires (UBA) participated.

In addition, the incidence of the development and implementation of prototypes using natural user interface technology as an educational, cognitive, and social complement in children with autism spectrum disorder was presented. It was developed by the National University of José C. Paz together with other organizations.

Another development that involves Argentine universities is the University Information System (UIS) to support university management. Barrera Nicholson et al. (2020) presented an analysis of this system in relation to disability. Among the main characteristics that lead to considering it as a technology for inclusive education, the following stand out:

- The SIU-Guaraní module manages the academic management of students, from when they become applicants until they obtain their diplomas. It is used massively by the majority of students, professors, and staff of the 55 Argentine universities; it contains the data of all the students, including data referring to disability. This means that every Argentine university has the necessary mechanism to collect safe, complete, consistent, and timely information regarding students with diverse needs, as well as using it to carry out concrete actions.
- Regarding digital accessibility, the UIS team takes into account, as guidelines, the WCAGs of the World Wide Web Consortium (W3C), 2020). In 2012, a thorough analysis of the portal of students and teachers of the SIU-Guarani was conducted, in order to evaluate its accessibility. The analysis was organized in three different stages: manual, automatic, and with users.
- To increase inclusion, a version that allows the application of gender identity regulations in the system was launched this year.
- Each module of the UIS ecosystem has the name of an indigenous community, also trying to include their students in some way. These modules are called Guaraní, Pilagá, Diaguita, Kolla, Mapuche, Sanavirón, Wichi, Araucano, Sanavirón-Quilmes, and Tehuelche.

Among other applications for inclusive education developed by Argentine universities, we can mention:

FINGER (Zurbrigk et al., 2012) is a computer tool based on free software meant to translate the Spanish language to ASL. It is a female humanoid who was baptized FINGER and who performs the ALS interpretation of a text in Spanish for people with hearing disabilities, allowing for a more inclusive educational proposal. This tool was developed at the National University of Comahue.

In the DANE Project of the Argentine Republic Down Syndrome Association (ARDSA) they develop applications designed for the education of children and young people with disabilities (ASL, Down, autism). Education specialists and technology programmers work together to develop these applications adapted to the specific needs of their recipients. They integrate computer technology into education, are cost-free, and can be downloaded and installed on any next-generation mobile device. The participating universities in this project are the UBA, the National University of Luján, the UTN, and the Argentine University of Business.

Ambrogio and Petris (2015) present a web application developed at the National University of the Northeast with educational games, which serve as stimulus and support to reinforce the priority learning nucleus with content related to numbers, vowels, means of transport, fruits, colors, and animals, for beginner-level students with mild intellectual disabilities.

Developments and Proposals in Local Universities

In this section, we present some developments and proposals based on ICTs that support an inclusive education, carried out by the authors of this chapter, at the UNSE and at the National University of La Plata.

Mathematics and Sounds App for Pupils with Hearing Impairment at the Preschool Level

As mentioned in "Technologies for General Learning," technologies for general learning, including mobile devices, are very important in inclusive education. In this section a mobile application for mathematics learning for preschool children is described. It facilitates learning in deaf children with cochlear implants.

Early language development in deaf children with cochlear implants has increased the number of hearing-impaired children entering mainstream schools (Kelman & Branco, 2009). But the successful insertion of these children depends on their hearing rehabilitation (De Reave, 2010). To contribute to this, researchers from the Institute for Research in Informatics and Information Systems (*Instituto de Investigación en Informática y Sistemas de Información* – IIISI) of UNSE are developing the application of mathematics and sounds. It is a multiplatform mobile application that uses 2D and 3D augmented reality visual resources to offer mathematics learning activities combined with auditory training activities. The proposal is based on the following referential framework:

- Mobile technologies have advantages in learning (Pachler et al., 2010): low cost, ubiquity, easy connectivity, situated learning, and motivation.
- Augmented reality allows adding contextual information from a scene in the real world to mobile learning applications (Arici et al., 2019). It favors attention and motivation (Brezovszky et al., 2019). Children with hearing impairments have a more developed sense of sight, which improves their visual attention (Dye & Bavelier, 2010).
- Main auditory responses for speech perception: detection, discrimination, identification, and understanding (Erber, 1982).
- Main math topics for preschoolers: number series, numbers up to 10, location (forward-backward, up-down, right-left), shapes, and measurements (large-small, curved-straight, round, square).

The main concepts of mathematics involved in the application are big-small, near-far, up-down, and numbers from 1 to 5. At the same time, the learning activities allow children to detect, identify, and discriminate sounds and phonemes that correspond to different frequencies. Some of the activities are carried out with augmented reality. Figure 1 shows the main menu of the application.

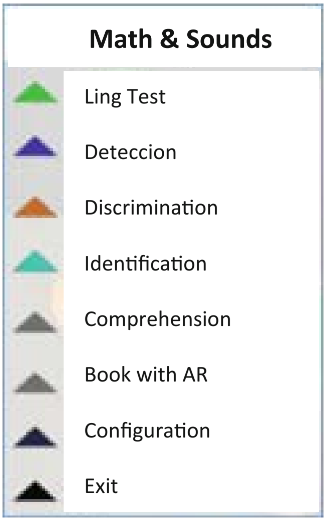


Fig. 1 Main menu of mathematics and sounds

Fig. 2 Avatar of mathematics and sounds

Since these are playful activities, they are animated by an avatar, called Mate, which was designed (color, name, texture, shape, movement) especially for children from two to five years old with hearing impairment (see Fig. 2). The application envisions that children will use the App with the assistance of adults who belong to their close environment (parents, siblings, educators, assistants).

The auditory training activities are combined with the previously mentioned mathematics contents. For example, in Fig. 3, a sound detection practice combined with the "big-small" mathematical concept is shown.

The App is in the coding and testing stage. Testing is carried out together with hearing specialists from the Hearing Impairment Program of the Province of Santiago del Estero. It should be noted that the App was included by UNESCO in the Compendium of Initiatives for Inclusive Education 2020 based on artificial intelligence and other innovative technologies (Herrera, 2020).

Fig. 3 Sound detection activity

Higher-Level Learning Environments for People with Hearing Impairment

Continuing with the developments for inclusive education based on the use of technologies for general learning, an application that runs on a personal computer and that facilitates the learning of adults with hearing loss in any area of knowledge is described below.

Chomsky (2003) affirms that speech acquired as children is a state of the power of language that belongs to human beings and of the experience of being exposed to the language spoken by their parents, teachers, and relatives, among others, which provides input that activates the mechanisms of language acquisition.

Based on this, Radelli (2001) created and designed a technique called Logogeny, where the input or trigger is the written language. It was developed in the 1990s in Mexico and extended through Italy, Spain, Colombia, Argentina, and so forth. With this technique, the subject gets to know the syntactic and semantic rules of his/her language. In Spanish they would know, for example, that the combination “ma” belongs to their language because they would have seen it in many words, but the combination “stchk” does not belong because they did not see it in any.

Based on the Logogeny method, Zampar (2019) presents satisfactory results in terms of the written linguistic understanding of those with hearing impairment. Study strategies linked to reading comprehension are defined, which accompany didactic activities in which principles of Logogeny are applied and implemented in a software tool called Logogenios.

For implementation, the first strategy study technique is created, which is well known and consists of highlighting parts of the text that are considered important. When necessary, a second study strategy is defined in brackets, which consists of a brief personal summary of the rest of the text which would not be convenient to highlight, but it would still be important to gain understanding of. This dual strategy study of both highlighting and making summaries is extremely useful for the third strategy, which consists in using the same digital pedagogical resource of the teacher, so that the people with hearing impairments can better understand the basic and fundamental bibliography used by the teacher. These study strategies are accompanied by didactic activities following the principle of Logogeny in relation to the aforementioned contents. The strategies and activities are incorporated into the software for a higher-level subject, in a four-point structure:

(A) Probable Partial Exam question (this is part of the structure, but it is not introduced into the software because the student shouldn't know the test question).
(B) Teacher notes after applying the strategies of highlighting and summary.
(C) Defining the type of minimum pair to be used in the exercise. Radelli op cit. (2001) presents the technique of minimum pairs as a fundamental part of Logogeny. These are two correctly written sentences that only differ by one element. Sarmiento and Valdeblanquez (2010) affirm that this minimal difference gives rise to the principle of opposition and allows the subject to realize the different meanings that the sentence acquires and advance in the process of incorporating their written linguistic competence.
(D) Questions that are related to points A and B are to be worked within the software. The answers offer several alternatives that the student must choose from, according to the type of minimum pair defined in point C.

Below is the name of the activity in Text Name and the number of questions in Number of questions; in this case there are six as can be seen in Fig. 4.

Fig. 4 New activity upload

Fig. 5 Response loading

lenguaje. Aparece en la publicidad.

El Par mínimo a utilizar son los lexicales: la diferencia está en una palabra. Ejemplo: Patea una caja-Patea una pelota.

Preguntas a trabajar con el software.
1. La función informativa es cuando el emisor intenta transmitir ...
2. La función apelativa es la que pretende convencer al ...
3. La función emotiva aquella que manifiesta una ...
4. La función fática es la que verifica que funcione correctamente ...
5. La función metalinguística se refiere a hablar sobre ...
6. La función poética se refiere a producir un hecho estético por medio ...

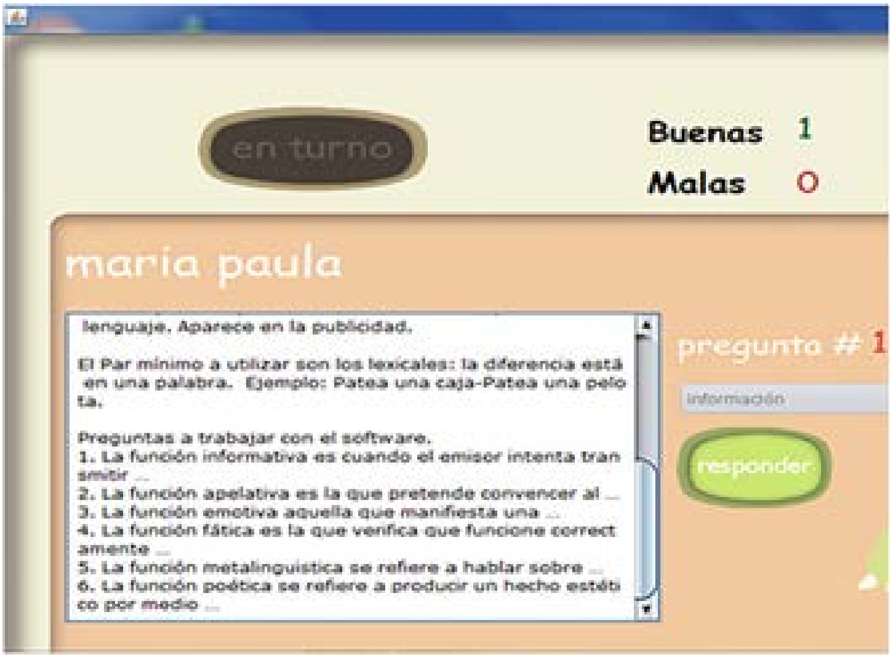
Respuesta Seleccionada: contexto

Fig. 6 Teacher's or administrator's window

The software responds with six windows as shown in Fig. 5 that allow adding the three possible answers to each of the six questions. At the bottom of the screen, the letter corresponding to the correct answer is selected.

Once the activity uploads have been carried out, Fig. 6 presents what is shown on the teacher's screen. Here we can see the buttons:

- "pass answer" to go to the next answer.
- "give turn" to give a turn to a specific student.



lenguaje. Aparece en la publicidad.

El Par minimo a utilizar son los lexicales: la diferencia está
en una palabra. Ejemplo: Patea una caja-Patea una pelo
ta.

Preguntas a trabajar con el software.
1. La función informativa es cuando el emisor intenta tran
smitir ...
2. La función apelativa es la que pretende convencer al ...
3. La función emotiva aquella que manifiesta una ...
4. La función fática es la que verifica que funcione correct
amente ...
5. La función metalinguistica se refiere a hablar sobre ...
6. La función poética se refiere a producir un hecho estéti
co por medio ...

Fig. 7 Student's window

On this occasion, the student María Paula is chosen in the select shift box and then pressing the "give turn" button.

When a student gives a correct answer, this is reflected on the student's screen in Fig. 7, with its rating as Good = **1**. And so on, different students are given turns to participate in the activity.

The work showed there's improvement in the acquisition of written linguistic competence. Students don't have contact with all the syntax of the language. Still, they are able to perfect their linguistic understanding and incorporate new vocabulary and better structures. People with hearing impairment notice how sentences are formed and the order in which the elements of a sentence should go, even if they do not know the language entirely. This happens in all languages; people end up knowing syntactic rules because they acquire them, and amazingly, this happens without anyone explaining it to them. They are also able to learn what are the exceptions to those rules.

Inclusive Communicator for Children with Cerebral Palsy

Child-Comm (Rosenzvaig et al., 2020) is an alternative communication system (ACS) for children with mild cerebral palsy, based on pictograms. It is an application for Android OS that can be run on phones or tablets. It was designed so that children with this disability can use it both in their educational activities and in their daily lives. It was developed in 2015 by the IIISI of the UNSE.

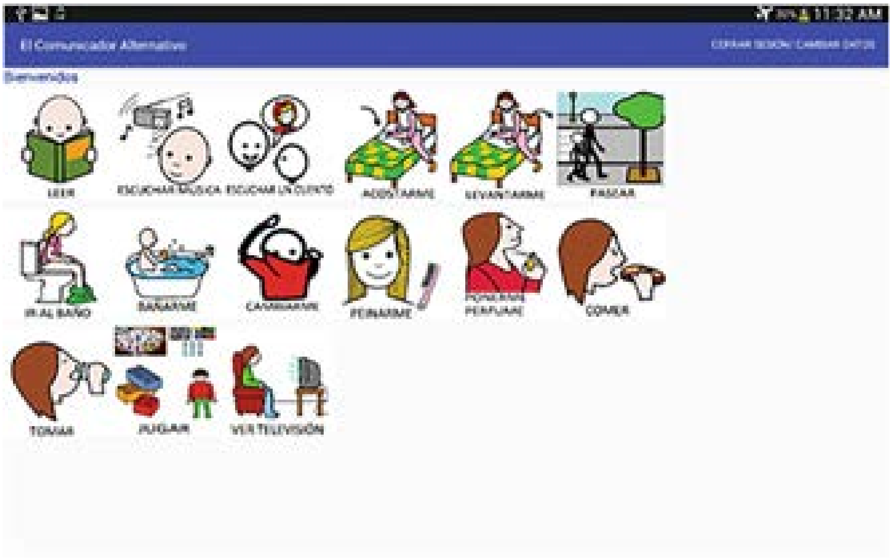


Fig. 8 Screen for a Spanish-speaking girl who is at home and wants to communicate what activity she wants to perform (Rosenzvaig et al., 2020)

ACSs allow replacing or expanding speech when it does not exist or is impaired, that is, they are tools that allow establishing communicative relationships with the environment that are put at the service of people with limited oral language (Stephenson & Limbrick, 2015). Examples of ACS are sign language, communication boards, and books with pictograms as well as electronic communicators that incorporate sound as output.

Child-Comm is framed within the tools that favor cultural diversity. The main characteristic that distinguishes it from other means of communication based on pictograms is the preservation of the Santiago culture, involving indigenous vocabulary and regional accent. Other outstanding features are the ability to adapt to some user preferences and that it responds according to location. In other words, Child-Comm offers alternatives and adapts according to age and sex, as well as according to the location of a child (educational institute or home). Figure 8 shows an example of the alternatives that Child-Comm shows a girl who is at home and wants to carry out some activities, while Fig. 9 shows the global navigation within the system.

The application has been tested in the Provincial Institute of Integral Rehabilitation of Santiago del Estero, with the collaboration of the therapists of said institution. Currently, the information storage and management module is still under development; this would allow optimizing the communication alternatives that would be offered to the child based on their history of activities and preferences.

Child-Comm was presented at national and international events with a wide level of acceptance in the scientific communities connected with technologies for people with diverse needs.

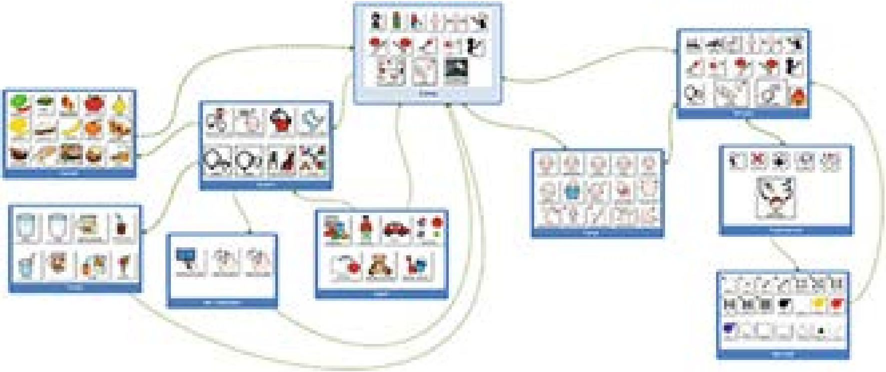


Fig. 9 Navigation scheme through the Child-Comm screens (Rosenzvaig et al., 2020)

Sustainable M-Learning Model for Isolated Regions

Argentina is a country with a large area (eighth in the world) that has isolated or remote regions that are not reached by conventional electricity distribution and communication networks. In addition it has mountains that make it difficult for these networks to arrive.

In some cases, these remote regions have alternative systems (e.g., solar-powered areas) that allow villagers to have limited power and data service. However, both the absence and the limitation of these resources prevent the normal development of basic human processes, such as the learning process. This difficulty was heightened during the COVID-19 pandemic period in these regions. A clear example of the situation in Santiago del Estero was presented to the world on the CNN news network in September 2020[1]).

Researchers from the IIISI of UNSE and the National University of Salta have been working on designing alternative, viable, and sustainable communication network models for education in these regions (Rocabado, 2020; Rocabado et al., 2013), as well as on defining effective learning strategies based on mobile devices or m-learning (Morales et al., 2018; Herrera et al., 2013).

In order to contribute to an inclusive education, which does not neglect people who live in remote areas, the aforementioned group has designed a low-energy communication network (intranet) model for m-learning in isolated rural areas.

The intranet is mainly made up of a server of services and digital educational resources, which is accessed by the actors of the learning process (teachers and students) through their mobile devices, using Wi-Fi or Bluetooth wireless communication technologies (see Fig. 10). The server is a single-board computer (Raspberry Pi). Both the server and the mobile devices are energy efficient and are powered by portable solar panels.

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[1] https://cnnespanol.cnn.com/video/estudiantes-viajaron-presentar-examen-virtual-pkg-omar-estanciero-perspectivas-buenos-aires/

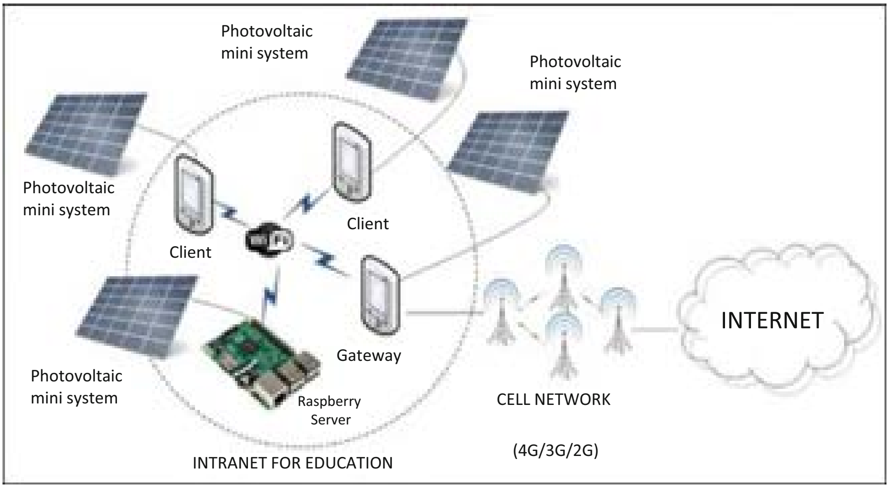

Fig. 10 Low consumption network model for education in remote areas (Rocabado, 2020)

To connect mobile devices to the Internet, a communications scenario is used, in which one of the cell phones acts as a communications gateway (between the intranet and the cellular network) and the rest of the devices connect to the Internet through it.

The full proposal – the network model plus the working procedure for educators – will be validated in educational centers in isolated areas of the province of Santiago del Estero. For this, specific m-learning practices will be designed for different areas of the curriculum, using the MADE-mlearn framework (Herrera et al., 2013). In some of the practices, the applications developed at UNSE will be used: ImaColab[2] and AlgeRA.[3] Currently, funding is expected from the national government to support the implementation and validation of the model in schools of various educational levels in the province of Santiago del Estero. In situ, other alternatives of Internet connection (satellite connection and fiber optics) will be further analyzed, as well as teaching without an Internet connection. All this will allow achieving a model that optimizes and reduces energy consumption in devices and communications, fostering sustainable learning.

Architecture Based on Ontological Models for the Development of Inclusive Ubiquitous Learning Applications

In the IIISI of the UNSE, work has been done on an architecture for the development of ubiquitous applications (Durán et al., 2014) that is validated with the construction of specific applications. Its versatility allows it to be adapted for the development of applications that are understandable, easy to use, and accessible by all people. Thus,

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[2] https://imacolab.com/

[3] http://algera.com.ar/

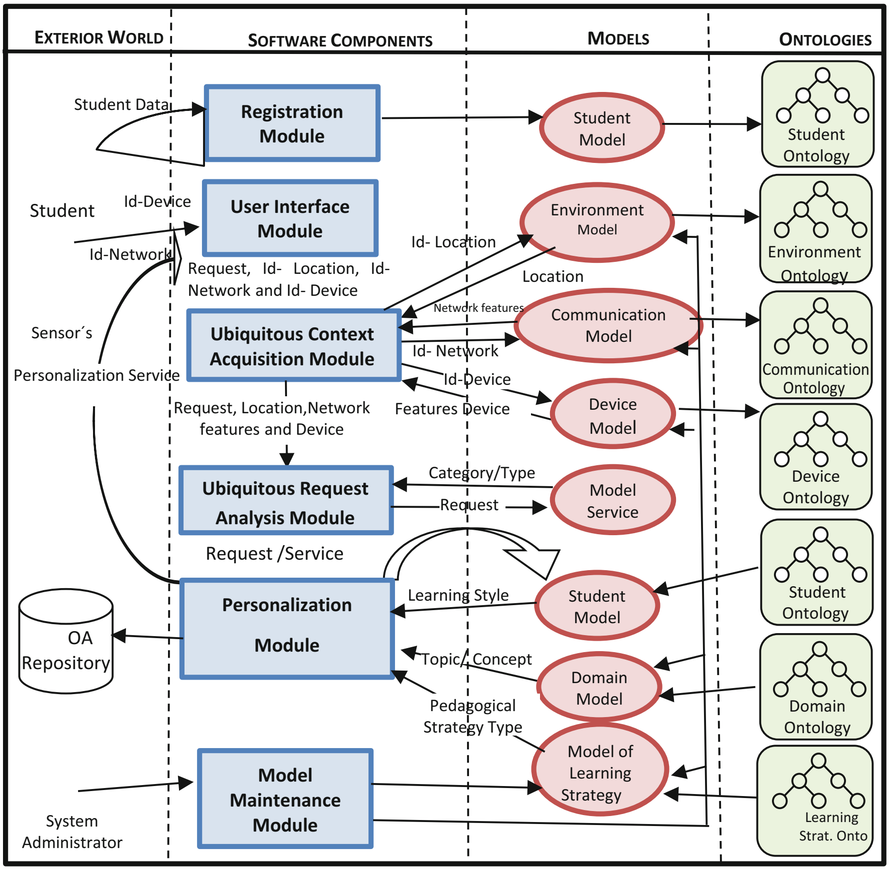

Fig. 11 Architecture for UL application (Durán et al., 2014)

ubiquitous learning (UL) applications that are developed on the basis of this architecture will favor inclusion.

Architecture encompasses four dimensions (see Fig. 11). The Models and Software Components dimensions, with the adaptation proposal for inclusion, are described below.

Models Dimension: All these models were implemented with ontologies.

- *Student Model*: describes the most relevant characteristics of the student for personalization purposes. It mainly contains information related to personal and academic data. To promote inclusion, attributes are added on diverse needs. This is essential for the customization of educational materials and services: for example, type of visual impairment (partial, slight, partial blindness and blindness), degree of hearing loss (mild, moderate, severe, deep), degree of motor disability (none, mild, moderate, severe, and very severe), and aborigines (name of the aboriginal people, language).

- *Domain Model*: represents the pieces of knowledge. Given that the model is designed taking into consideration the IEEE-LOM standard for learning objects (LOs), which does not include accessibility characteristics, it is necessary to advance in our research and make proposals that allow us to properly map the student's profile with the accessibility characteristics of the LO. Also, a transformation of the LOs already made is necessary so that they contemplate these characteristics.
- *Model of Learning Strategy*: describes the various actions that can be used to enable largely meaningful learning in the context of UL. It contains information regarding type of strategy (trial and error, with pre-orientation, full composition, etc.), tools (e.g., navigation, interaction, audio, video, and images), activities (questionnaires, tasks, problem solving, essays, etc.), and evaluation system.
- *Device Model*: describes the UL devices and those belonging to the group of assistive technologies to be used in the learning processes.
- *Communication Model*: describes the types of communication networks to be used in the learning processes.
- *Environment Model*: describes the different environments (home, university, street, etc.) in which the UL can be completed, and the interest points (IP) found in those environments. When considering an inclusive education, it is feasible to incorporate other learning environments such as rural areas, marginal areas, and aboriginal communities.
- *Social Context Model*: describes the people who can collaborate in any way in developing activities with the student (peers, tutors, experts, etc.).
- *Model Service*: describes the educational services that an application can offer to the student.

Software Components Dimension: the following software modules have been considered:

- *User Interface Module*: it oversees communication with the student, including their identification, the course to be taken, and the learning service request. In addition, it responds to the requests of the student. The user interfaces are adapted according to the needs of the student, considering the standards for accessibility.
- *Ubiquitous Context Acquisition Module*: captures the coordinates of the student's position, the network and the device used by the student, and the IP identification.
- *User Request Analysis Module*: determines the type of service that the student requests.
- *Personalization Module*: it has to do with adapting the services based on the personal and pedagogical characteristics of the student and the ubiquitous context, recommending LOs.
- *Model Maintenance Module*: provides support for initializing and updating models whose data is dynamic.

From the architecture based on ontological models, five personalized services have been designed that are offered to students in ubiquitous contexts. The following describes each of them.

Service 1: This service displays to the student a personalized list of LOs in relation to a specific IP. The first version of the application accounts for the customization of LOs based on learning style. However, it is feasible to incorporate adaptation to other characteristics of the student's profile to favor an inclusive education.

Service 2: This service offers a personalized learning path for the student, based on the selection of a learning objective and considering the current location of the student.

Service 3: This service recommends a list of nearby IPs according to the current location of the student, as long as they have not yet been visited by the student.

Service 4: The service offers the student a list of experts who are currently online or who are close to the student's location, to advise the student in the completion of a specific task.

Service 5: The service recommends a group of peers who are physically close and who can best support the applicant student in their learning, depending on the degree of progress in the task and the level of knowledge.

Thus, the architecture presented opens a way for the development of UL applications that are accessible to other groups not considered in the original proposal but that can be included with minimal adaptations.

Conclusions

Inclusive education is not limited to access to ordinary schools for students with diverse needs but rather seeks to minimize the barriers that limit learning for students from various social groups, ethnicities, cultures, and beliefs, and with different behaviors, thus avoiding exclusion and discrimination. This chapter shared a look at inclusive education in Argentina by taking these aspects into account, as well as the fact that both these barriers and the resources to diminish them can be found within schools, in the community, and in local and national policies.

The chapter began with a review of the legislation that supports all the actions that can then be carried out, since, although inclusion is the responsibility of the entire society, the state must be the one that guarantees the right to quality education for all. Currently, the Argentine educational system has made important advances in the regulations concerning the rights of students. Public policies are guided by these laws; particularly, those related to promoting equality, inclusion, and educational achievement for all students.

After this, we presented actions that were carried out by Argentine universities to favor the inclusion of different groups. In this regard, it can be concluded that actions for inclusion have increased significantly from the 1990s to the present day; this is manifested in the teaching and learning processes and in the other functions of the university—research, extension, outreach, and management—even though these advances do not occur to the same extent in all institutions and in relation to all different groups.

In addressing the role of ICTs as tools to support inclusive education, we presented some examples of developments carried out in Argentine universities in the search to increase accessibility and inclusion of students. However, at the same time, when ICTs are used in non-inclusive contexts, they are tools that can further increase the differences between people, generating more exclusion in the field of education. It is necessary to consider that these technologies have a high cost, which means that only a few have access to them. In Argentina, as a consequence of the economic crisis experienced during the last 10 years, access to assistive technologies has been increasingly expensive, since these are usually solutions that come from abroad, with costs that are calculated in dollars. Therefore, it's even more important to develop local solutions in the national territory, thus avoiding importation. Some projects that have been developed in different Argentine universities and, in particular, in UNSE and UNT help with this goal. However, even those efforts are scarce. Much remains to be done toward the inclusive use of ICTs and the development of software applications that promote inclusive education.

It can be concluded though that important advances were made in regulations and numerous concrete actions and technological developments were carried out in order to promote inclusion. All of these allow for the value of diversity to be affirmed strongly. However, there is still progress in building more accessible educational materials, in training teachers in the use of ICTs that promote educational inclusion, and in supporting the implementation of new proposals such as Universal Learning Design. UDL should be oriented not only toward changing pedagogical practices but also as a tool for developing contexts.

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Inclusive and Equitable Education in Postcolonial Caribbean

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Zoya Shepherd

Contents

Abstract

In a society riddled with the long-term economic effects of colonialism, access to inclusive and equitable education directly impacts that society's ability to innovate and actively participate in the rapid unfolding of our globalized futures. The present-day Caribbean education model perpetuates systemic segregation which continues to place barriers on societal growth. As a region, the Caribbean has been in a period of rapid transformation for a while, where entire industries are changing, identity is in constant flux, and the role people play in the productivity of world affairs is increasingly questionable. Considering the many

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vulnerabilities that the region faces, Caribbean nations need to actively participate in creating a new kind of future for themselves.

Opportunity lies in the untapped potential of the creative economy, and thus the possibilities of redesigning education to better equip the youth to engage creative thinking in their lives is necessary. Centered in Barbados, this study aims to bridge the gap between the need for creativity in the economy and the lack of teaching adequate creative thinking methods in the school curriculum, by introducing a flexible way for teachers to explore implementing creative thinking methods in classrooms across a variety of subjects. The design of accessible and practical tools allows the shifting of critical consciousness of both teachers and students alike, to co-create more inclusive and robust local communities.

Keywords

Critical pedagogy · Design thinking · Inclusive education · Decolonization · Caribbean education · Creative thinking

Introduction

In the 1960s, British Caribbean nations sprung out of colonial power into independence with a revolutionary vision: self-sustained, self-educated, and self-governed economies. In Barbados, the idea was to build a nation that operates on pride and industry and produces a quality of life capable of rivaling larger imperial nations. In many ways, this was accomplished, but the model that allowed for this growth is now over 50 years old, and the world is in a period of rapid globalization with constant technological changes that continue to transform businesses and decrease the need for traditional labor.

The Caribbean Development Bank cautions that the Caribbean could become "the poorest region in the world by 2050" if the ease of doing business is not addressed by its member states (Ram, 2020). The CDB director explained that after two decades, the region's Gross Domestic Product (GDP) per capita dipped below the world average in 2016. Their 2018 "*Sustainable Caribbean Economy*" report listed key challenges facing the region include "macroeconomic, productivity and competitiveness, human development and environmental" (Ram, 2020). No longer is it a case of just having a high quality of education, but instead it's a case of having an education that can adequately prepare students for this new global era. The same applies to employment and business, where the functionality of these roles needs to rapidly adapt to continue being useful and competitive. Failure to adapt could mean that the region loses the ability to be an active contributor to the future.

The Caribbean's sustainability lies in the intrinsic talent and values which are found there. There is a uniqueness about the Caribbean in that it's so diverse and yet so connected; fractured by distance but inhabiting all the shores of the Atlantic with shared history and customs. The region is rife with creativity, but as relatively new nations, creativity has not been the focal point of economic development. Local attitudes often consider the arts as a thing of pleasure, not a fundamental need, but research shows there is an untapped potential of the creative economy.

The Inter-American Development Bank states that “creativity is the inexhaustible resource in Latin America and the Caribbean” known as the “orange economy,” and that “creativity as a driver of innovation can contribute to diversification as a necessary tool for having a globally competitive knowledge-based economy” (IDB, 2017). In 2016, the World Economic Forum listed in their publication “*The Future of Jobs*” that the third most needed skill for work by the year 2020 was creativity, preceded only by the ability to solve complex problems and critical thinking. To put it in context, the workforce of the entire worldwide orange economy is larger than that of the European, Japanese, and US automotive industries. “In 2015, the orange economy in Latin America and the Caribbean sustained a number of jobs comparable to that generated by the entire economy of Costa Rica or Uruguay” (IDB, 2017).

The creative expressions of the Caribbean are distinct but have remained somewhat contained to a local or grassroots level. Creativity cannot be understood here without the context of class. In almost every area of the arts, there is some form of education needed to fully learn and master the craft and thus Caribbean artistry has not yet flourished into self-sustained and profitable industries robust enough to contribute to the economy. Music is the exception to this rule, possessing the unique ability to transcend the narrow pathway and access points of money, education, or social connections. Music has become a monument of the working-class structure by pushing new genres into the global consciousness that will outlive us all. The evidence of this is around the world, not just in the Caribbean.

The objective of this study is to explore how creativity can be nurtured in Caribbean culture to empower Caribbean nationals to move towards a new mirror image – one that supports cultural identity, imagination, and innovation. Given that the Caribbean is geographically vast with multiple languages spoken, this study is localized to Barbados as a starting point to inspire a model that can provide further critical examination and exploration across the region. This research tackles the education system on the premise that it is impossible to have a generation of creative innovators fueling the economy if the education system doesn’t produce creative thinkers.

Literature Review

Education and economics are deeply connected. The school environment is where people are trained and prepared to be a part of the workforce, and therefore economic futures begins in the classroom. Barbados is known globally for its high standard of education and boasts a literacy rate of over 98%, providing state owned and run education at primary and secondary school levels. In 2016, The World Economic Forum ranked the school system ninth in the world in its “*Global Competitiveness Report*,” an accomplishment for a relatively new and small nation. Success though, is not a static thing and success requires context. The Caribbean suffers from the “brain drain,” which the Inter-American Development bank questions as a possible “curse of small states” and reports that “small states had a brain drain rate five times that of all developing countries, 12 times that of high-income countries, and eight times the world average. In the Caribbean, a region dominated by small states, the percent of tertiary educated that emigrate ranks among the highest in the world” (IDB, 2016).

The brain drain in Barbados occurs because the economy is largely dependent on tourism and low-skill labor for the limited exports the country produces. The economic base is relatively undiversified, and there is less demand or opportunity for skilled labor and higher educated persons to fully utilize their capabilities. These factors mean that the government pumps millions of dollars into the education system annually but much of that investment leaks right back out of the country. This impacts local businesses trying to attract top talent, and it also thwarts the nation’s growth towards the competitive edge in a rapidly globalized future. The education model is outdated and will contribute to the nation’s inability to thrive moving forward. Understanding how this education model came into existence is important to chart where it should go to next.

A History of Exclusion

The Caribbean education system is deeply rooted in colonial practices where education began exclusively for plantar-class children. Boys of the elite plantar class were encouraged to pursue education, whereas girls were directed more towards domestic studies. “Prior to independence, colonial educational systems in the English-speaking Caribbean continued to be elitist and to serve the purpose of reinforcing economic and social hierarchies in Caribbean societies” (Pilgrim et al., 2018). This perpetuated segregation by keeping working-class people at the bottom of the social ladder preventing upward mobility and allowing only a small number of high-achieving students access to elite gender-segregated secondary schools. Post-slavery, education became charity-based for poor whites and discouraged for people of color and further progressed to a present-day system of ability grouping. “Ability grouping typically involves the separation of students into particular groups based on their perceived ability levels. In the case of Barbados, the Common Entrance Examination is used as a tool to stream students into secondary schools at different levels of perceived ability. Then, within those hierarchically based schools, further streaming of students into classes of different ability levels is also typically undertaken” (Pilgrim & Hornby, 2019).

The Barbados Secondary School Common Entrance Examination (BSSCEE) was implemented in 1959 in an attempt to achieve a more effective quality education which awarded students access to secondary schools based on ability and not on socio-economic or racial backgrounds. In Barbados, this selective schooling process (leftover from British colonialism) was developed out of a clear need to reduce discrimination to secondary school entrance by the school’s administrative boards.

In many ways, this was an act of pre-independence from Great Britain to establish local control and create a more inclusive model than what previously existed.

The Need for Change in Barbados' Education System

Despite providing more equal opportunity in sitting the Common Entrance Exam, after more than 60 years the system still reinforces aspects of segregation. This model (ability grouping) has "implications for educational outcomes, the social inclusion of all children, and the provision of an equitable education system" (Pilgrim et al., 2018). For example, the top four schools in Barbados' education system produce the nation's scholars while the majority of prison inmates come from the eight lowest-ranked schools.

In June 2019, Mia Amor Mottley, the Prime Minister of Barbados, set an initiative to restructure the school system for more inclusivity and equity by abolishing the Secondary School Common Entrance Exam. "We have reached the point where we need to reject an approach to education that was settled by the British in the 1940s" (Barbados Today, 2019). The Prime Minister proposed the introduction of middle schools which would give students the chance to uncover their strengths and have more learning options suitable to varying capabilities between the ages of 11 and 13 before moving on to secondary school. Currently, the school structure mimics the British system, where primary school runs from ages 3 to 11. The Common Entrance Exam is then done at age 11 and then sorts students into secondary school, which runs from ages 12 to 16 (Forms 1–5). The top four secondary schools have a Form 6 (Lower and Upper 6) which runs for another 2 years until graduation at age 18. Admission into sixth form is also highly competitive, as there are only four schools. Alternatives to sixth form remain the local college, polytechnic, or directly to university with an additional foundation year added to their program.

For many years in Barbados, there has been criticism of the education model's ability to produce high-level critical thinking despite being considered a leader in Latin America and Caribbean education affairs. Evidence of subpar performance presents itself at a later stage in life when students are exiting the secondary school level and either lack the minimum requirement of four certificates to enter the workforce and further haven't developed soft skills necessary for working with people. Dr. Marina Alfonso, a Senior Education Specialist at the IDB assessed research findings and shared, "We're seeing that students are not necessarily well prepared to support an economy that is based on knowledge and innovation . . . and that, based on a 2012 survey, Barbadian employers shared the same complaint as their Latin American counterparts that school leavers lacked necessary soft skills – the ability to work with other people, the ability to lead, to think critically. . ." (Barbados Today, 2016). This has always been considered a sticking point to societal growth in Barbados because as a small-island state primarily dependent on tourism for economic growth, these are obvious disadvantages to allow to continue festering for the sake of the economy.

Caribbean nations experience restrictions on economic growth due to export transport costs on goods and therefore have begun looking to the creative economy to leverage the sustainable talents of its people. Creativity in the Caribbean has untapped potential to transform the economy since it's "based on talent and creativity, which are not only renewable, but are the source of innovation and new content." However, there are limitations to growth that are rooted in the education and training on how to effectively capitalize on creative talent and "these deficiencies adversely impact the skills set, knowledge, and knowledge pool in the sector" (Hendrickson et al., 2012).

Regardless of the lens used to explain creativity, its importance is recognized on a global scale with respect to economic, political, and educational landscapes. In the Caribbean (and Barbados), creativity is engrained in daily life; with limited resources a resourcefulness is born. Social perspectives on creativity tend to be limited to creative disciplines like art or music, and these unfortunately aren't high on economic return. There is limited opportunity for creative persons to fully capitalize on their creative outputs despite passionately wanting to capitalize their ideas – there is a lack of knowledge on how to do this because it's not included in the standardized high-stakes exam-based curriculum.

Classroom Approach to Creativity

The study "*A Comparison of Barbadian and Grenadian Teacher's Beliefs About Creativity*" revealed that most teachers think of arts-based subjects to be more connected to creativity than science-based subjects, despite research studies showing that neurologically, there are no differences in brain and cognitive responses here. This is clearly connected to the cultural identity of creativity – a perspective in need of shifting. The study recognized there is a "creativity gap" between what is valued and what is actually practiced and that teachers perpetuate this when they appreciate creativity, but do not alter practices to include creative learning. Results from this study revealed that while teachers felt they were creative and understood the need for creativity, they were not optimistic or convinced about their own "strength in creative problem-solving" and "teaching creative thinking" (Jackman & Young, 2017). The disconnect between the desires of students to utilize their creativity (or even recognize they are creative) and the ability and confidence of the teachers to facilitate this process is apparent.

This begs the question, what is needed to teach creative thinking in the classroom? A study *"Creative Thinking in the Classroom"* found that teaching in a way that encourages, and rewards creativity can improve school performance. The study revealed that to a large extent, creativity is not just a matter of thinking in a certain way, but rather it is an attitude toward life. "In teaching students to process information creatively, we encourage them to create, invent, discover, explore, imagine and suppose" (Sternberg, 2003) and that part of adopting this creative attitude is to make decisions which underlie creative thinking. They identified 12 key elements that make up this attitude: (1) redefine problems; (2) analyze your own ideas; (3) sell your ideas; (4) knowledge is a double-edged sword; (5) surmount obstacles; (6) take sensible risks; (7) willingness to grow; (8) believe in yourself; (9) tolerance of ambiguity; (10) find what you love to do and do it; (11) allowing time; (12) allowing mistakes (Sternberg, 2003).

The study "*Fostering Problem Solving & Creative Thinking in the Classroom*" was conducted over 1 year with the aim of uncovering the type of learning environment that promotes creative thinking and problem-solving skills in students. The study revealed that "the classroom climates that promoted creative thinking and problem solving were: open, comfortable, relaxed, challenging, safe, supportive, trusting, humorous, energized and collaborative" (Hamza & Griffith, 2006). The researchers also observed the need for teachers to challenge the imagination and encourage innovation. "Challenge their learning through experimentation, novelty, and originality – not through their abilities to memorize. Help students to progress gradually from being memorization-dependent to become independent thinkers and problem solvers" (Hamza & Griffith, 2006).

These studies provide a preliminary understanding of the requirements to teach creative thinking in the classroom, but refocusing on the Caribbean, this area remains to be explored. As the government of Barbados prepares to restructure the school system to a model more reflective of inclusion for all students regardless of social background and academic ability, support tools are needed to facilitate this change by unearthing the value of creative thinking in the classroom setting as an alternative to the rigid high-stakes curriculum founded on a "banking model" of education that no longer fully serves its society. *Pedagogy of the Oppressed* by Paulo Freire speaks of removing this banking model in favor of more democratic problem-posing-education, as the banking concept of education is an instrument of oppression, whereas the problem-posing concept of education is an instrument for liberation.

Creative Thinking – Although there are many opinions and cultural perceptions on what creativity is, the approach for this project was to clearly define "creativity" and "creative thinking" with respect to the previously mentioned study conducted in the Caribbean by Jackman and Young. Creativity is defined as a "novel product, idea, or problem solution that is of value to the individual and/or the larger social group" (Hennessey & Amabile, 2010). Creative thinking is therefore the process used to generate appropriate and new ideas to solve problems. Based on this definition, the curriculum of the 11–13 age group was surveyed to find an entry point into the school system and found the Visual Arts curriculum listed "creative thinking" as one of its curriculum objectives. This reflected the misperception revealed in the previously mentioned study, that creativity necessarily equates to applied arts.

The teaching structure in Barbados could also contribute to failing to meet the curriculum objective of "creative thinking." Primary school teachers are predominantly "class teachers," responsible for teaching a single class all of its subjects, for the exception of more specialized subjects like music or physical education. Secondary school teachers are subject specific, responsible for a cross-section of age groups but a focused subject matter. This means that often in the primary schools, Visual Arts is being taught by someone not particularly skilled or trained in the arts. This could also contribute to the lack of confidence in teaching creative thinking and often results in art activities that have preset outcomes and don't necessarily challenge the student's thinking. Visual Arts isn't included in teacher training in Barbados, but it is very much expected on the job.

Decolonization – This study is built upon Paulo Freire's theory of critical pedagogy detailed in *Pedagogy of the Oppressed* which aims to awaken critical consciousness. The goal of critical consciousness is the ability to identify, critique, and challenge the social forces and structures that produce or perpetuate the inequity and oppression you may find yourself experiencing or witnessing. It is concerned with the mind as the key for changing circumstances and thus is a suitable theory for this study considering the identified need for creative thinking in Caribbean education. Consideration is also given to the fact that critical consciousness does not fully address the likes of decolonial theorists. As detailed in "*Decolonization Is Not a Metaphor*," "Colonialism is marked by its specializations. In North America and other settings, settler sovereignty imposes sexuality, legality, raciality, language, religion and property in specific ways. Decolonization likewise must be thought through in these particularities" (Tuck & Wayne Yang, 2012). Much of decolonialization work is concerned with the repatriation of indigenous land and life and questions the role of critical consciousness as a possible distraction for the real decolonization work that needs to be done.

There are some differences in the Caribbean being a region where most Indigenous people were eradicated as a consequence of colonialism, which somewhat changes the landscape of possible Indigenous repatriation. The vast majority of modern-day Caribbean people are of African ancestry and the reality of being a descendant of enslaved Africans is that the connection to ancestral land and identity has been lost – ruptured in the middle passage. Therefore, whereas Indigenous futures are often concerned with the revival of past life, Afrofuturism is about creating the future. It is here that the efforts of this research are focused; to consider the future that critical consciousness can awaken amongst Caribbean people, and as an act of decolonization, decide for themselves how to apply the creative thinking in this study towards changing the learning structure of the current education system.

Methods

This research asks the question: *How can we enable teachers to teach creative problem solving in the classroom?*

The purpose of this study was to prototype and evaluate a toolkit to facilitate educators in teaching creative problem-solving exercises in Barbados classrooms. This research explores a way to equip teachers to foster creativity in students by building upon the existing visual arts curriculum with the intention of empowering teachers to have the confidence to teach creative thinking skills. This study used a mixed-methods design where qualitative and quantitative data were collected by way of questionnaires and a research workshop.

This study was reviewed and approved by the Research Ethics Board (REB) at OCAD University.

Recruitment

Considering that the 11–13 age group are the students most vulnerable to educational changes which the government of Barbados proposes, a combination of primary and secondary school teachers was needed. A private school in Barbados was selected for this workshop because they have both primary and secondary schools together, which provided more flexibility in teacher recruitment and coordination for the workshop. Once REB approval was given, the school was contacted by email to participate in this study and a recruitment poster was sent out to the teachers.

Eight teachers participated and taught either visual arts, the 11–13 age group or both to ensure a cross section of teaching experience within the workshop. All participants completed an informed consent form prior to the workshop commencing and were given opportunity to ask questions before submitting their consent.

Questionnaire

A two-part questionnaire was designed to measure the efficacy of the workshop. The first part was administered to the participants at the start of the workshop which focused on capturing their confidence level teaching creative thinking as well as their beliefs and thoughts on what creativity is. At the end of the workshop, the second part of the questionnaire was administered, which captured their response to the activities in the study and their perception of confidence in teaching creative thinking moving forward.

Prototype

A prototype was designed and evaluated in the workshop to leverage the teachers' participation. A framework, teaching methodology, and subject were implemented into the prototype.

Framework

A Design Thinking framework was used to build out the curriculum. Design Thinking is described as "a non-linear, iterative process which seeks to understand users, challenge assumptions, redefine problems and create innovative solutions to prototype and test" (Interactive Design Foundation, 2020). This approach often allows people who are not in creative disciplines (such as the participants of this study) to use creative tools to solve problems. There are five stages of design thinking: (1) empathize; (2) define; (3) ideate; (4) prototype; and (5) evaluate. The stages of this framework offered an opportunity to incorporate an art activity beyond the typical approach of art lessons in Barbados. Since this framework is by nature a human-centered approach to creativity, this aligned with the need to merge art education and socio-economic matters.

Learning-by-Doing

Learning-by-doing means "learning from experiences resulting directly from one's own actions, as contrasted with learning from watching others perform, reading other's instructions or descriptions, or listening to others' instructions or lectures" (Reese, 2011). A "learning-by-doing" approach to stage 1 (empathize), stage 3 (ideate), stage 4 (prototype) was applied. Stage 2 (defining the problem space) was predetermined and framed into a project case study. Stage 5 (evaluation) was not used in this workshop.

Subject

In order to anchor this framework into the culture as an example of connecting arts to society, a cultural object was selected, and the five-stage framework was designed around it. The object of the workshop was the Bajan Snow Cone vendor, and the workshop was broken into three activities. The participants worked in two groups of four.

- Activity 1 – empathy building promoted the participants to explore an empathy map and a customer-user experience for the snow cone vendor. Following this, a different case study problem surrounding the snow cone vendor was presented to each group.
- Activity 2 – ideating and prototyping were combined, and the participants worked in their groups to generate ideas to solve the problem their snow cone vendor was experiencing.
- Activity 3 – here, the participants deconstructed what they learned and restructured how they would introduce these creative problem-solving methods to their classroom and other teachers. This prompted them to consider the immediate use of this framework in their classroom teaching.

Data Analysis

The collected data was systematically organized into concepts and emerging themes following grounded theory coding procedure. Open coding was used to reveal the key concepts from the workshop discussion with the participants.

The categories were organized similar to the questionnaire by revealing the participants' perspectives before the workshop activities and after. These participants' perspectives and themes were tracked, and the results informed the components needed for the prototype.

Results

Questionnaire

Eight teacher participants were surveyed and answered all questions in both the pre- and post-workshop questionnaires. Their responses were organized into three sections:

A. understanding where the teachers were at *before the activities*
B. the activities they found most impactful
C. what resonated with the teachers most *after the activities?*

Where the Teachers Are at (Before Activities):

Participants were asked to define creativity, to define what a creative person is and whether or not they believed they were a creative person. They were also asked to define creative thinking and whether or not they felt confident in teaching creative thinking skills.

On Creativity

While each response to defining creativity was expressed individually, the general consensus was that creativity involved having the ability to express oneself, to think and solve problems. For instance, participant 1 defined creativity as “the ability to use your imagination to problem solve or express an emotion or a concept,” while participant 2 said, “creativity is the ability to approach a problem/activity with many different perspectives, not knowing in advance what is right or wrong, and being able to solve the problem by bringing multiple dimensions to it.”

On a Creative Person

When defining what a creative person was, the responses aligned with the perception of creativity by illustrating a person’s ability to innovate or think outside of the box. Participant 2 stated that “a creative person uses anything (information or stimulus) to make something new or to enhance a particular concept using prior knowledge/experience.” One participant’s (4) definition deviated slightly here by defining a creative person as “one with a flair for colors, visual expressions, precision and fun.”

On Considering Themselves to Be Creative

Additionally, seven of the participants considered themselves to be creative, and only one participant was on the fence about calling themselves creative and explained that they had the ability to be creative but was inconsistent.

On Creative Thinking

The overall responses to defining creative thinking identified some connection to problem solving and thinking up ideas beyond the traditional expectations. Here are some examples: Participant 2 said, “creative thinking allows an individual to think ‘outside the box.’ Critical thinking skills are enhanced through the method,” and participant 6 said, “creative thinking is being able to use a variety of approaches to problem-solve or create a vision. It employs skills from all subject areas and multiple intelligences.” Participant 8 said, “creative thinking is about being able to make connections, apply emotional intelligence, be reflective about your own mental models and question generally; all of which engages problem solving.”

On Confidence Teaching Creative Thinking

Prior to engaging in the workshop activities, four of the participants felt confident in teaching creative thinking; two participants (participant 4 and 6) did not feel confident teaching creative thinking; and two teachers (participant 1 and 3) were uncertain of their ability to teach creative thinking expressing they felt somewhat capable but believed that they needed more practice or resources to build their confidence and become more effective. Participant 3 explained, "I am more confident fostering creative thinking in students who already have some – even just a little. I find it very difficult to improve creative thinking in students who are challenged in the area."

On Everyone's Capacity to Be Creative

When asked if they believed that everyone has the capacity to be creative, six of the participants replied yes, and two participants replied maybe and expressed that they felt some people had more natural ability to be creative, where as some people needed more assistance and teaching to develop the skills. For instance, participant 5 said that it "depends on what creativity means and what they are being creative about, for example the visual arts – not everyone has the ability to be creative in that field/area if they are not 'visual' or understand certain abstract concepts as they relate to the visual arts."

The Workshop Activities That Were Most Impactful:

The opportunity to reflect on the workshop lessons and activities were presented here and the participants responded to the four components. They were allowed to select more than one option in this section to indicate the most impactful and valuable activity.

- Three participants found the lesson on Human Centered Design to be most impactful.
- Six participants found that activity 1 (empathy building) was the most impactful.
- Five participants found that activity 2 (ideate and prototype) was most impactful.
- None of the participants selected activity 3 (deconstruct and reconstruct) as most impactful or valuable.

Empathy building was overwhelmingly the most impactful activity to which the teachers commented on its value. Participant 2 said about activity 1 (empathy building), "this was the most interesting part for me as I was able to explore the empathy map with the snow cone vendor and his feelings at my level of the process." Participant 4 shared "activity 1 allowed me to get in touch with the character – it gave me an understanding of the character and helped me to visualize the person's way of thinking." Participant 5 said about activity 1, "from this activity, other lessons/approaches can emerge. It gives a very deep insight into the characters/culture/situation which is crucial in understanding and solving or creating."

What Resonated the Most with Teachers (After Activities):

The participants were surveyed to understand which activity was the most immediately useful in their classroom teaching. They were also asked if felt they could recommend these creative problem-solving methods and based on what they learned from the activities, if they felt confident teaching these creative thinking methods.

On the Most Readily Usable Activity

The response showed that six participants felt that activity 1 (empathy building) was the readily useful for their existing classroom sessions. One participant opted for activity 2 (ideate and prototype), and one participant responded that both activities 1 and 2 were most immediately useful for their classroom sessions.

On the Most Usable Activity for Visual Arts Lessons

Upon reflection, four participants felt that within an art class they would immediately use activity 2 (ideate and prototype), two participants opted for activity 1 (empathy building), and one participant felt all of the activities were usable. The final participant noted they were unsure, and it can be noted that this participant met the participation criteria of teaching the 10–13 age group but did not teach visual arts at all and thus felt reluctant to answer specifically to visual art classes.

On Their Confidence Teaching Creative Thinking

The response showed that seven of the participants felt they could implement the methods they learned into their class teaching and existing curriculum, and the same seven participants now reported feeling confident in teaching creative thinking. Only one teacher said they could not implement these methods into their class and also said no to feeling confident teaching creative thinking. This was participant 5, who also said no to feeling to confidence teaching creative thinking at the beginning of the workshop, but expressed that while they understood the concepts and methods taught in the workshop, they still lacked confidence because they felt they needed more practice with these new methods before implementing them with students. Other participants who answered yes to feeling confident teaching these methods did also note they would still like additional sessions to become more familiar with the material.

On Recommending These Creative Problem-Solving Activities

All participants said they would recommend the methods taught to them in the workshop to other teachers.

Themes from the Research Workshop

The workshop facilitated two mini-discussions before and after the activities, and from this dialogue and their responses to the concepts they learned throughout the workshop, themes were identified.

Before Activities

The participants already felt a need for change in teaching methods as they regularly face many challenges with students and resources. They were open to learning something new with regards to creative thinking but held a lot of apprehension with the current school system and the limitations it places on them, as these limitations were seen as not conducive to what they considered necessary to fostering creativity in the classroom.

Motivation

The general motivation to attend this workshop was a recognition that they had existing challenges teaching creative confidence and that there was an overall shift in the student body's information intake and that a new approach was needed to present content to students because the general system was outdated. The participants were interested to discover a possible new approach they could try out in their classrooms. For example, participant 8 mentioned that with some subjects, students are exposed to overlapping content over the years and aren't always meeting new information. "So, they feel like "oh we're doing this again." An interest in finding more creative ways to deliver the content was this teacher's motivation to attend the workshop.

Pressure

The teachers feel immense pressure to meet the requirements set out for them by Caribbean Examination Council (CXC) the governing body of educational development in the Caribbean. They feel strongly that there are too many subjects which make the students become stressed and there are also too many deadlines. Additionally, with a heavy workload it becomes hard to balance content delivery with the timing of syllabus requirements because of the nature of high- stakes-exam culture. Participant 5 said, "What I do not understand about CXC is that they come up with all these objectives that are supposed to help us, even though they aren't the ones doing it. Yet they have all these SBAs (School Bases Assessments) … children are bogged down … if you're doing 7 or 8 or 9 subjects they're stressed out!" This teacher further expressed, "We've voiced that as teachers and of course they ignore us. So, they're saying they want this. . .but we don't have the resources and we don't have the time. The children are stressed with all of this work and marks. And we've got deadlines. . .this, this, this and this! So, you're not only teaching skills, you're teaching to a deadline."

The SBA (School Based Assessment) is a set of asks/assignments/projects conducted in the school; carried out by the student following guidelines provided by CXC and assessed by the teacher using criteria provided by CXC. The SBA score contributes to the candidate's overall examination grade.

Perception

There was a belief that a relaxed environment was needed for creativity to thrive and the culture of education in Barbados was so heavily marks driven that it didn't help nurture this creativity. Participant 1 said "What is it we really want from the students? Because my experience is when you want creativity to flow you want people to be relaxed. I am most creative when I'm not pressured. But it's hard to remove that pressure when they need marks for the curriculum." The teachers felt that the current teaching model does not work for creativity and that the Caribbean has a very traditional mindset, and this presents a major challenge to changing the current system. Participant 4 expressed, "I actually think that you cannot teach the same way and try to be creative. It has to be a whole change! And I think once you are comfortable within that new shape then things can be implemented more smoothly. Within this new shape it will happen seamlessly... but it's because our mindset is still so traditional, we will have a challenge."

Time

Teachers are constrained by a lack of resources, and they do not feel seen or heard by the authorities whose objectives are too demanding. They find that they are constantly working to deadlines and there's lack of flexibility in the requirements CXC sets for them to meet in the syllabus. Trying new things takes away from the limited time they have to hit the markers to prepare students for their exams. Participant 5 shared, "I have to teach a program that is driven by 'you have to do this...you have to do that'... and it does not allow me to teach it in a slightly different way because then I cannot fulfill the requirements of the syllabus because I've got this deadline and that deadline. I've tried one or two things, but it has taken away from time." And participant 8 echoed, "it takes me half the class or even the entire class to get them involved and help them to understand and find examples and connect them to that [topic] before we even get into what the rest of the content looks like, before we can even begin to annotate, before we can even deconstruct text for them to be able to create something that they can write and take the information behind."

Evaluation

There are high expectations held by the government which continues to perpetuate the marks-driven culture that constrains the growth of students and flexibility of the teachers. Due to this marks-driven culture, even parents have high expectations, and this creates no middle ground for experimentation. Participant 1 noted that "in education it's still the authorities have designed something and then you're given it and you need to execute it properly because those marks are very important. We're still very much afraid to experiment." Participant 8 shared "I do think we are heavily marks driven and I do think that parents and teachers and children...all of us need to question the mental model about that. How much scaffolding do we do? How much of it that is behind the scenes is going to make the child successful from simple of executive function skills." Participant 6 said, "the whole education system we have is it's either right or wrong. There's no middle of the road."

After Activities

The participants shifted their focus to the activities and how they could implement the methodologies they learned. Empathy building was the tool they connected with the most, and this prompted them to explore alternatives for evaluation as this was an area in need of change in order to nurture a more creative environment. Additionally, the need for collaboration amongst the participants is an area for future growth.

Empathy

Participants found that the empathy-building exercise allowed for a mindset shift to occur. They liked that it encouraged engaging in your environment and exploring scenarios to problem solve. Additionally, it was positive that the exercise required you to embody another person or situation, express your point of view and encouraged asking questions to switch your thinking. Participant 8 mentioned, “I think that process of empathy helps a lot. . .even if you don’t have all the specialty knowledge, it helps to create a shift.”

Evaluation

Self-evaluation or peer review is an alternative to the marks-driven culture. Encouraging work where there is no set right or wrong answer reduces expectations and allows building imagination and creates more options for students to explore work where they can express themselves more. For example, participant 4 explained, “I liked the part about no wrong answers because I find with my Form 1’s. . .after all this common entrance preparation, it’s really hard for them to believe that two different answers can both be right, because that’s not what they’ve been prepped for. . . so, something like this that teaches them that there are many right answers, it’s a really good way to start shifting that.” Participant 3 remarked positively in the option to “encourage students to think of new ideas to bring to a task or topic. . .so encourage students to be freer in [their] expression. . .to understand there are many solutions, and that no answer is wrong. . .it may just be more or less applicable.”

Objective

A change in approach to the classroom objective is possible where teachers can flip the script and think from the perspective of the learner and build content materials from that angle. Speaking for the second group of teachers, participant 8 explained, “we were thinking about was to kind of flip the script a little bit and have the teacher think about what would it be like to be the learner . . .and so to see the objective from not what I have to deliver but what I have to learn. . .and from that perspective to then reflect a bit about the students perspective on what they might be getting. . .so we were thinking about the level they’re at to so we begin to create something that is visible to them.”

Support

Collaboration and community are needed to succeed. Teaching can be an isolating job when you are alone in the classroom all day, and in some departments, you may be the only teacher of your subject. Opportunity to share ideas and get feedback is critical. As explained by participant 6, “One of the problems is we don’t have enough people in the departments to brainstorm with. If you’re having to teach a class, you’re brainstorming with yourself. And that doesn’t help!”

Key Insights

There are a few key things that came out of the discussion and themes in this workshop which I think should be noted.

1. ***Work Within Constraints*** – the most noticeable shift pre- and post-workshop was the focus on external pressures. Prior to engaging the activities, there was a lot of dialogue and concern about the constraints placed on them. After the activities,

the teachers were less focused on the external pressures placed on them and began to explore ways, they could fit existing requirements within this model. This is to say, the confidence seemed to come from working within constraints, not by removing constraints entirely.

2. ***Establish Connection*** – The most impactful activity which the teachers also found easiest to implement into their class sessions was empathy building. Their remarks revealed that empathy building brought about a sense of connection, both with characters and the environment as well as with their own students. It also was the catalyst to connecting to the other steps of framework. It prompted the teachers to consider their approach from another perspective – the students.
3. ***Reframe Expectations*** – It resonated with the teachers the reframing of evaluation metrics in teaching creative thinking. Specifically, the notion of there being no wrong answer, and exploring different ways of assessing outcomes seemed much more possible with this framework and these activities than in the traditional curriculum. Prior to workshop activities, the dialogue allowed no alternative for grades, but afterwards, they were considering possibilities.

The significance of working within constraints is in considering the factors of decolonization and working in a postcolonial society. It is incredibly difficult to completely dismantle existing global socio-political structures that are so deeply engrained in us, but it is possible to be critically aware of those structures and work consistently to push against their borders and move them further outwards until a new paradigm has been created. Connection is multifaceted, as it also presented itself in the need for support and collaboration amongst the teachers and cannot be ignored as a catalyst to developing empathy and strengthening skillsets amongst students in a classroom setting. Where this makes a mark is the benefit of decolonial work to be grounded in solidarity. Strengthening the power base of a society can increase resiliency and cultural identity. Reframing expectations extends beyond evaluation or grades. This allows certain freedoms rarely experienced in colonized communities. The freedom to be in control, to explore, and to initiate ideas develops a different attitude among people.

These key insights and most impactful activities from the workshop informed a model for teaching creative thinking in the classroom.

Design Decisions

The design solutions were informed by the feedback to the workshop and the model illustrating how to teach creative thinking in classrooms (Fig. 1). Together, these informed the next iteration of the workshop design and the teacher's toolkit. Overall, the workshop needs to be extended to allow more time for discussion and the flexibility to go in-depth in the activities. The workshop should be a minimum of 4 hours in order to facilitate this approach. Additionally, there needs to be an opportunity to debrief (or quickly discuss) after each activity to capture more specific and isolated feedback to each stage of the workshop. Given the feedback captured in the questionnaires, the participants need an opportunity to take away the materials and

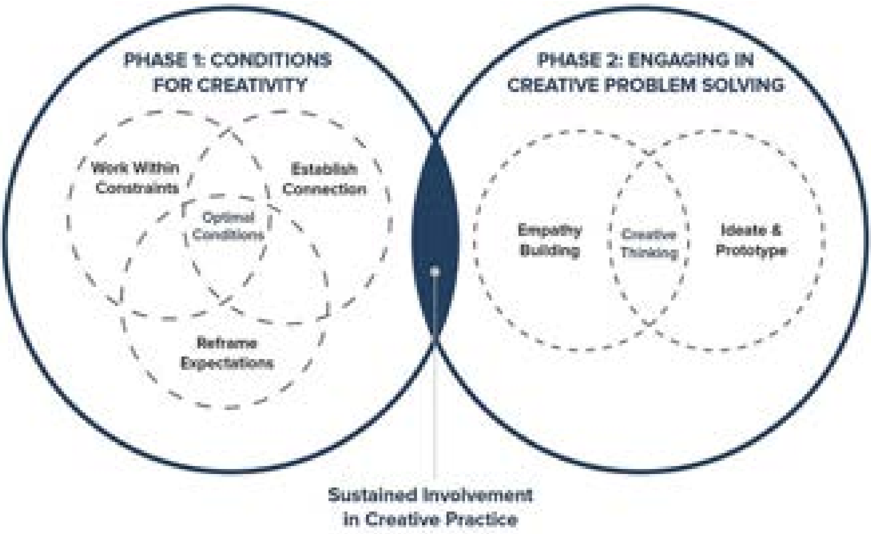


Fig. 1 Model showing how to teach creative thinking

practice these activities in their classroom to get more familiar with the material. Therefore, the prototype designed is intended to be multi-functional and allow the toolkit to be used in the workshop as well as independently by teachers (Figs. 2 and 3).

Prototype Design

The design solution for the teacher's toolkit has two components:

1. A manual for teaching creative thinking
2. Activity cards for classroom implementation

Manual for Teaching Creative Thinking

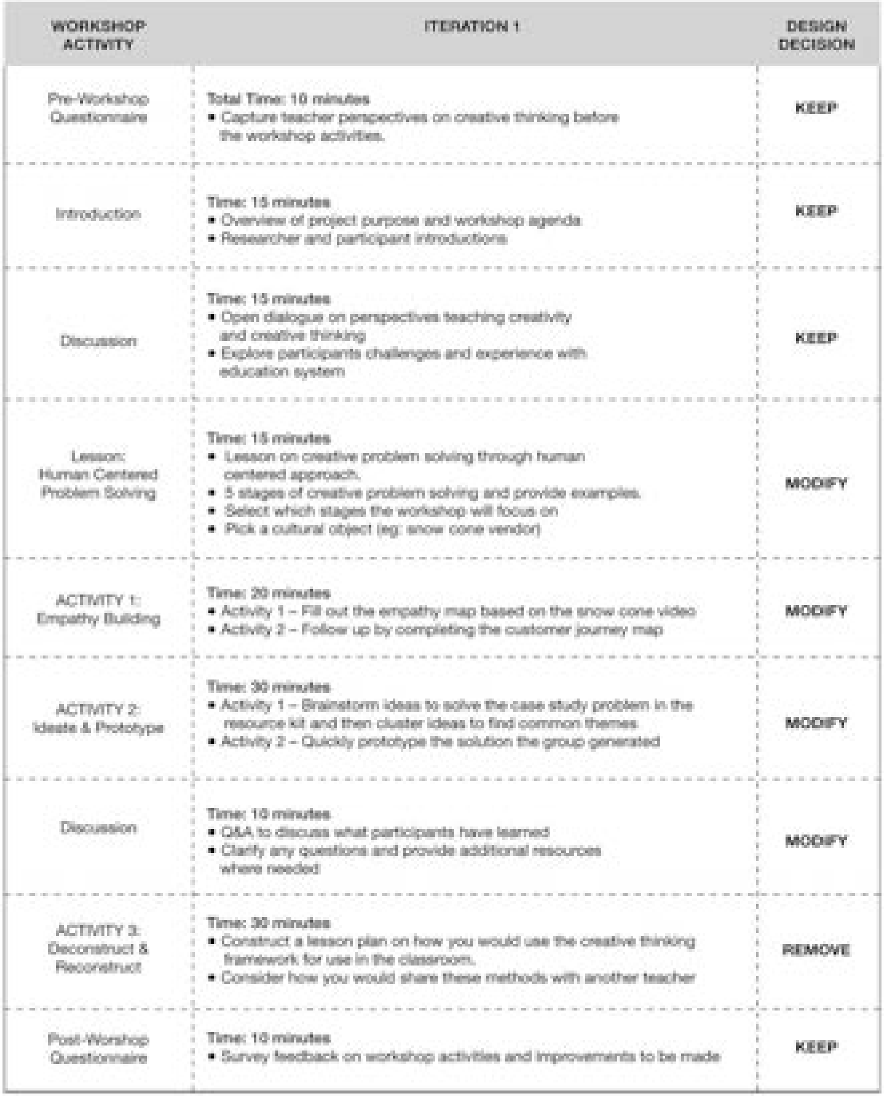
The purpose of the manual is to facilitate further workshops with more narrowed focus on activities and content that is most impactful to the teachers (Fig. 4).

What's Inside the Manual

- Overview of creative thinking and human-centered approach to problem-solving
- Three-step framework for creating the conditions for creativity
- How to activate and engage in creative thinking

Activity Cards for Teaching Creative Thinking

The purpose of the activity cards is to integrate the workshop methods into classroom settings and engage problem solving with students. The aim is to cultivate imagination building in students.

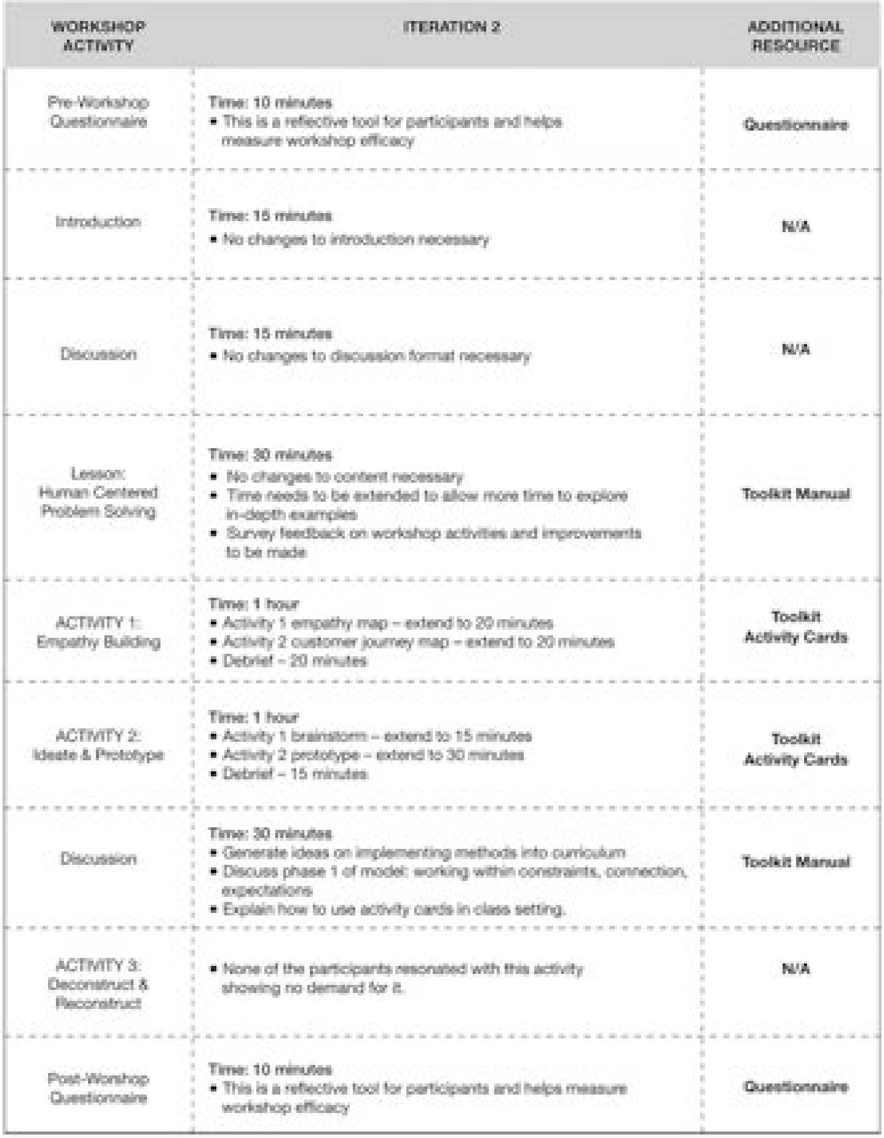


WORKSHOP ACTIVITY	ITERATION 1	DESIGN DECISION
Pre-Workshop Questionnaire	Total Time: 10 minutes ▪ Capture teacher perspectives on creative thinking before the workshop activities.	KEEP
Introduction	Time: 15 minutes ▪ Overview of project purpose and workshop agenda ▪ Researcher and participant introductions	KEEP
Discussion	Time: 15 minutes ▪ Open dialogue on perspectives teaching creativity and creative thinking ▪ Explore participants challenges and experience with education system	KEEP
Lesson: Human Centered Problem Solving	Time: 15 minutes ▪ Lesson on creative problem solving through human centered approach. ▪ 5 stages of creative problem solving and provide examples. ▪ Select which stages the workshop will focus on ▪ Pick a cultural object (eg: snow cone vendor)	MODIFY
ACTIVITY 1: Empathy Building	Time: 20 minutes ▪ Activity 1 – Fill out the empathy map based on the snow cone video ▪ Activity 2 – Follow up by completing the customer journey map	MODIFY
ACTIVITY 2: Ideate & Prototype	Time: 30 minutes ▪ Activity 1 – Brainstorm ideas to solve the case study problem in the resource kit and then cluster ideas to find common themes ▪ Activity 2 – Quickly prototype the solution the group generated	MODIFY
Discussion	Time: 10 minutes ▪ Q&A to discuss what participants have learned ▪ Clarify any questions and provide additional resources where needed	MODIFY
ACTIVITY 3: Deconstruct & Reconstruct	Time: 30 minutes ▪ Construct a lesson plan on how you would use the creative thinking framework for use in the classroom. ▪ Consider how you would share these methods with another teacher	REMOVE
Post-Worshop Questionnaire	Time: 10 minutes ▪ Survey feedback on workshop activities and improvements to be made	KEEP

Fig. 2 Design decisions of workshop iteration 1

How the Cards Work

- Step 1: Pick one of each type of card to create a narrative
  - Pick an archetype (vendor, bus driver, nurse, etc.)
  - Pick an activity (selling snow cones, treating a patient, making a delivery)
  - Pick an empathy card (says/thinks/does/feels)
  - Pick a problem card (various human problems: back pain, anxiety, no money)



WORKSHOP ACTIVITY	ITERATION 2	ADDITIONAL RESOURCE
Pre-Workshop Questionnaire	**Time: 10 minutes** ▪ This is a reflective tool for participants and helps measure workshop efficacy	**Questionnaire**
Introduction	**Time: 15 minutes** ▪ No changes to introduction necessary	**N/A**
Discussion	**Time: 15 minutes** ▪ No changes to discussion format necessary	**N/A**
Lesson: Human Centered Problem Solving	**Time: 30 minutes** ▪ No changes to content necessary ▪ Time needs to be extended to allow more time to explore in-depth examples ▪ Survey feedback on workshop activities and improvements to be made	**Toolkit Manual**
ACTIVITY 1: Empathy Building	**Time: 1 hour** ▪ Activity 1 empathy map – extend to 20 minutes ▪ Activity 2 customer journey map – extend to 20 minutes ▪ Debrief – 20 minutes	**Toolkit Activity Cards**
ACTIVITY 2: Ideate & Prototype	**Time: 1 hour** ▪ Activity 1 brainstorm – extend to 15 minutes ▪ Activity 2 prototype – extend to 30 minutes ▪ Debrief – 15 minutes	**Toolkit Activity Cards**
Discussion	**Time: 30 minutes** ▪ Generate ideas on implementing methods into curriculum ▪ Discuss phase 1 of model: working within constraints, connection, expectations ▪ Explain how to use activity cards in class setting.	**Toolkit Manual**
ACTIVITY 3: Deconstruct & Reconstruct	▪ None of the participants resonated with this activity showing no demand for it.	**N/A**
Post-Worshop Questionnaire	**Time: 10 minutes** ▪ This is a reflective tool for participants and helps measure workshop efficacy	**Questionnaire**

Fig. 3 Design decisions of workshop iteration 2

- STEP 2: Generate the case study/narrative based on the cards (make it seamless)
- STEP 3: Ideation – allow students to engage in a group brainstorm and discussion
- STEP 4: Prototyping – group or individual project that is student-driven; teacher-guided (Figs. 5 and 6).

The prototype of the toolkit manual and activity cards is available for download and user testing at: www.thisiscontexture.com

Creativity is an attitude towards life.
To teach creative thinking requires fostering
the right mindset and environment.

THE CONDITIONS
FOR TEACHING
CREATIVE THINKING

There are 3 simple things we can do to start creating the conditions for creativity in the classroom.

Work within constraints
Establish connection
Reframe expectations

1

Fig. 4 Sample page of the toolkit manual

Future Work

The following are some next steps to consider in further design development of the prototype:

Smaller Focus Groups

It was extremely advantageous to have a high number of participants in this study, but in order to continue fine-tuning the workshop to maximum impact, more time needs to be allowed for each activity. This can be achieved by working in smaller groups and pairing participants together during the activities.

Teacher–Student Co-Design

The activity cards need to be tested in a class setting with a teacher and students. One teacher to three students should be sufficient to try out the activity cards by subject to continue the iterative design process.

Subject Specific Workshop

This workshop can be explored across more subjects in the educational curriculum. For example, a workshop of creative thinking for science teachers, history teachers, or math teachers will yield further data to help develop different versions of the prototype.

Fig. 5 Archetype card and activity card

Limitations

This study was conducted at a private school where resources are more accessible than public schools. It would be beneficial to test the workshop prototype with public school teachers to understand further challenges that they may have, which may not have been considered or realized within a private school setting.

Furthermore, the scope of this research is limited to Barbados, which serves as an accessible model for other English-speaking Caribbean nations. It is without doubt, however, that the French, Spanish, and Dutch islands will require significant adaptations to this study to respect their individual histories and existing school systems.

Conclusion

The goal of this study was to introduce a practical tool to assist teachers in implementing creative thinking methods into classroom sessions. The intention was not to dictate specifically how to use this tool in their curriculum, but instead to give teachers a framework that empowers them to make changes where they feel most capable. And in doing this, begin to shift the perception and attitude towards creativity and visual arts as an optional component of Caribbean education.

EMPATHY CARD

SAYS

THINKS

DOES

FEELS

CHALLENGE CARD

Financial

Construction

Health & Wellness

Family

Fig. 6 Empathy card and challenge card

The Sternberg study introduced the elements that make up a creative attitude, and upon reflection and analysis, it's clear that these elements align with the key insights found in this study. Specifically, redefine problems, allowing time, allowing mistakes, and selling ideas. There is no fundamental difference in teaching creative thinking in the Caribbean compared to other regions. It is simply a matter of cultivating a learning environment and integrating methods that allow for creativity to flourish. Thus, this research study afforded a pedagogical toolkit to facilitate further workshop studies, as well as a model that illustrates the requirements for nurturing creative thinking in the classroom.

The use of the questionnaire both pre- and post-workshop allowed for the effectiveness of this research to be measured by mapping the confidence level the teachers had before and after their introduction to the creative problem-solving methods. The themes that arose from this research workshop perfectly grounded the toolkit components; empathy, ideation, and prototyping. Future studies should expand the scope to public schools to understand the unique challenges that arise in different school settings to allow for further adaptive workshops. The biggest insight from this study is the importance of teachers to challenge the imagination and encourage innovation amongst students. Thus, there is a need to design for more pedagogical flexibility in instead of the rigid structures that currently inhibit the Caribbean.

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Interdisciplinary Center on Open and Accessible Educational Resources: 10 Years Building Inclusive Education in Uruguay and Latin America

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Virginia Rodés and Regina Motz

Contents

Abstract

The year 2020 undoubtedly marks a turning point in the integration of digital technologies in education. The physical distancing necessary to contain the Covid-19 pandemic has highlighted the need to approach digital education from a holistic and critical perspective on its capacity for inclusion and exclusion. The Interdisciplinary Center for Open and Accessible Educational Resources (CIEDA) intends to consolidate and expand the approach to the subject of inclusive, open, and accessible digital education, in Uruguay and Latin America, implementing teaching, research, and third mission activities that provide scientific and technical knowledge for innovation, professional and academic practice, integrating diverse disciplines, producing a comprehensive approach, and giving rise to interdisciplinary and transdisciplinary collaboration. The interdisciplinary and intersectoral development in the university together with other social actors

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contribute to the informed development of the action of civil society and the government, in the creation of public policies, in permanent dialogue with reference centers of the region and the world. The center is an effort to consolidate the work that has been carried out since 2015 by the Interdisciplinary Group of Open and Accessible Educational Resources together with works of different stakeholders from society. Currently, the center is expanding its scope to three cross-cutting areas for the generation of open knowledge and human development: digital media and educational technologies, education and open science, ethics, and digital rights. On these transversal areas, interdisciplinary and intersectoral lines of work articulate efforts in teaching, research, and third mission, with social appropriation and transferability (products and services): skills for digital citizenship; data and artificial intelligence for education; diversity, equity, and inclusion in education; and critical digital pedagogies. The chapter presents the main developments made during a decade of work aimed at educational inclusion in Uruguay and in Latin America.

Keywords

Open education · Inclusive education · Interdisciplinary

Introduction

Nowadays it is inevitable to consider education in the context of the digital transformation of our society; the imperative of open education in its broadest inclusive sense is highlighted. This includes, mainly, open access to educational opportunities, without economic, gender, race, accessibility, or territorial barriers; open access to educational resources for their use, reuse, adaptation, retention, and redistribution; open learning, with the flexibility of time, place, and pace of learning; and open access to education from diversity and equity as guiding principles of value.

Inclusive education means giving all students a fair chance to learn with the same high-quality education and develop the skills they need to have an autonomous life. In this sense, the possibility that open education offers to facilitate personalized adaptations makes it possible to address diversity and inclusion.

The year 2020 undoubtedly marks a turning point in the integration of digital technologies in education and the revitalization of open education. The physical distancing necessary to contain the Covid-19 pandemic has highlighted the need to approach digital education from a holistic and critical perspective on its capacity for inclusion and exclusion. Digitization brings with it many new opportunities, but it also poses significant challenges that cut across education.

Digital technologies can promote flexibility and creativity and help improve efficiency and learning outcomes. But at the same time, phenomena such as false news, misinformation, excess of information, cyberbullying, rights violation in digital spaces, violation of data privacy, unethical uses of artificial intelligence, deviations in the algorithms that classify student profiles and teachers, and uncritical integration of technology are some of the threats that attempt to further marginalize vulnerable groups from quality education.

Interdisciplinary Center for Open and Accessible Educational Resources

Addressing the complexity of the challenges posed by open and accessible education requires multiple perspectives to be taken into consideration. The Interdisciplinary Center for Open and Accessible Educational Resources (in Spanish NúcleoREAA) integrates academics from the Universidad de la República (Udelar), the main public university of Uruguay, who contribute from different perspectives to the subject. The existence of NúcleoREAA makes it possible to capitalize the efforts of these groups, allowing the interdisciplinary approach that is expressed also in the heterogeneity of the more than 30 researchers, both from their training and their academic professional career, in disciplinary fields like Education, Technologies, Information, Communication, Sociology, Anthropology, and Law, among others. Joined by academics from the country and foreign universities, together with the Education Training Council, National Public Education Administration, and civil society organizations – like Uruguayan Association of Librarians, Creative Commons, and National Union of Blinders of Uruguay – they frame their experiences and developments together, based on numerous projects and initiatives carried out.

These projects and initiatives allow researchers to "learn with," "learn from," and "learn about," developing interpersonal skills for teaching, research, and third mission, within interdisciplinary teams and intersectoral dialogue. The commitment to collaboration, added to the technical, pedagogical, and research contributions, results in the quality of the task to be carried out and has a direct impact on the conception, design, and development of the construction of knowledge in this interdisciplinary field. Interdiscipline is the result of disciplinary elements (ideas, methods, theories, and practices), which are interactive, not additive, and subject to negotiation and creative adaptations based on the needs of the particular context (Graff, 2015). This form of interdisciplinary work was learned and apprehended by most of the members, through their direct participation in the projects and actions carried out. An overview of its main achievements can be seen in Fig. 1.

The NúcleoREAA then becomes the workspace where the various disciplines that compose it are dedicated to the problem of open and accessible education in an interdisciplinary way, articulating their different epistemological, methodological, and practical views, in order to exceed their borders in achievement of the objectives.

Interdisciplinary Areas of Development

The NúcleoREAA is organized in interdisciplinary areas. These development areas are mainstreaming interdisciplinary and intersectoral approaches, building a conceptual and methodological basement on which teaching, research, and third mission

Fig. 1 Overview of main achievements of NúcleoREAA

initiatives are built. This approach allows to enhance the process of collective construction of the subject, as well as the research results and participation in its social appropriation.

Areas

The transversal areas are A1) digital media and educational technologies; A2) open education and open science; and A3) ethics and digital rights:

A1) Digital media and educational technologies. Today, digital media are part of the culture and govern behaviors, trends, and languages that emerge from the digital environment and go through in an invisible way. Education must be studied in a contextualized way, and today the context includes digital media, because citizens are on social media. Van Dijck (2016) argues how the increase in various technological platforms generates a plot and outcome that encourages people to transfer aspects of their lives, both social and professional, as well as cultural, to these spaces, which is why it is imposed as a need. The implementation of a solid media education is urgent.

The new media have been permanently integrated into the learning and teaching processes. However, this simple statement has many important implications. Transformation refers mainly to opportunities related to the democratization of education, social inclusion, and sovereignty over the data they record and produce. Undoubtedly, the use of technologies allows crossing many borders. It is not just a question of geographical restrictions, but of accessibility in a general sense, also those derived from disability or belonging to disadvantaged groups. Educational technologies converge services for the creation of educational resources, repositories of educational resources, Learning Management Systems, Content Management Systems, Recommender Systems, Educational Data Mining services, Learning Analytics, and platforms such as Blockchain that allow distributed and secure transactions between these services. Within NúcleoREAA, we shape this area as a space of synergy between social sciences and technology, from a sociotechnical approach (Bijker et al., 2012).

A2) Open Education and Science. Open Education and Open Science constitute two key elements for the transformation of the models of creation and access to knowledge and culture. Open education encompasses the entire cycle of teaching and learning processes, open designs, open pedagogies, and open educational resources as part of the curriculum and integrated into the so-called new literacies. In higher education, there is no open education without open science. Making open science the dominant paradigm of scientific practice means promoting that publications, data, practices, methodologies, and processes derived from research are accessible to the scientific community and society. It also involves citizens in research environments and socially responsible innovation initiatives. The open science and education movement breaks down barriers to equity by expanding participation. It also reduces the historical effects of educational colonization: language problems, contextual gaps, lack of cultural diversity, and educational privilege. It is not a panacea for solving all problems in a global society or in the higher education sector, but it does become an advocate for sociocultural dialogue.

Work has been done on the articulation of education and open science through educational action-research projects developed within academic professional learning communities (APLC) in the context of public education in Uruguay (Czerwonogora & Rodés, 2019a, 2019b) as fundamental frameworks to face the challenges of critical educational action research, as well as collaborative and participatory technologies for the transformation of teaching and educational research practices. The approach combines the community dimension of the APLC and the openness toward research, favoring the construction of Open Educational Practices and the development of Open Science competencies.

In the context of this area, NúcleoREAA aims to identify, analyze, understand, and propose actions that help to adopt a truly open access approach, and inform and reinforce existing and prospective open education and science initiatives in Uruguay and Latin America, through the development of common strategies with principles that promote diversity, equity, inclusion, and activities for social participation in education and science.

A3) Ethics and digital rights. NúcleoREAA's members share the vision that both creation and access to knowledge occur in a social context and exercise of power that is not free from conflicts and inequalities. That is why we incorporate this area, which studies and analyzes, from an interdisciplinary perspective, the impact of digital technologies in education according to ethical aspects and digital rights. This contextual and critical look is supported using models and processes that we understand to be fair and sustainable, developing the concepts of accessible and inclusive open education, open science, and open data. People with disabilities or minority groups face complex challenges in leveraging media and contents for education and social participation. In a context of neither access nor universal design, technology in fact creates new challenges for literacy, equity, and autonomy.

According to (González & Grzona, 2016), the right to education has an even more relevant weight, when thinking of this period as that of the knowledge society. Work has been done on proposals aimed at the digital rights of people with disabilities within the project "Digital and accessible library (Bidya): Digitization of Libraries within the framework of compliance with the Marrakesh Treaty" (Díaz-Charquero et al., 2017; Díaz et al., 2019; Patrón et al., 2019; Rodés & Motz, 2020). Work has also been done on the protection of personal data in learning analytics projects (Díaz et al., 2015; Macarini et al., 2019; Macarini et al., 2020; Cervantes et al., 2018) applying the principles of "Privacy-by-Design" in the development of educational information systems from the integration of computer science with law, education, and communication, also developing new literacies in copyright and data use.

In response to the continuous transformations of digital technologies, this area ensures compliance with ethical principles and digital rights in all educational experiences that take place in new contexts and communities.

Lines

On the three abovementioned base areas (A1, A2, and A3), NúcleoREAA is organized into 4 interdisciplinary lines, promoting the interactions and intersections between the different disciplines in the development and implementation of teaching, research, and third mission actions, from their design, methodology, and transferability.

These 4 interdisciplinary lines are: L1) skills for digital citizenship; L2) use of data and artificial intelligence; L3) diversity, equity, and inclusion; and L4) critical digital pedagogies:

L1) Skills for Digital Citizenship. The technological immersion that we live in the various areas of daily life, including education, generates the need for skills and abilities not only to face the demands that this entails, but also to achieve a better exercise of rights. In this line, it is proposed to continue with the work from a comprehensive approach to various competencies related to digital citizenship: digital competences. In this line, it is proposed to continue with the work from a comprehensive approach to various competencies related to digital citizenship: digital competencies (Gewerc et al., 2017), information competencies (Díaz Costoff, 2015; Cabrera Castiglioni, 2015; Ceretta & Gascue, 2015), OER and OEP (Núcleo REAA, 2018; Núcleo REAA, 2019), data (Atenas & Podetti, 2019), and copyright (Díaz et al., 2017; Secker, 2018).

It is essential that teachers acquire digital skills that allow them to develop and transmit their knowledge in the digital age. Uruguay, to date, is working on the development of a digital citizenship framework. The Agency for Digital Government, Information Society and Knowledge (AGESIC) launched a public consultation in June 2020 to contribute to the digital citizenship strategy that includes among its lines of action the development of capacities in three dimensions: "Responsible and safe use," "Critical and reflective use," and "Creative and participatory use."

In addition to the need to assess digital skills, there is also an urgent need for a teaching digital skills framework that involves teachers, not only as users but also in the leading role of builders of our digital society and agents of curricular change. Likewise, the digital competence of university students is scarcely studied in Uruguay, and along these lines, work will be done to better understand the impact of public policies on educational, digital, and social policy aimed at developing digital skills to which the country has made numerous efforts in the last decade.

L2) Use of data and artificial intelligence. As technology evolves, the application of advanced techniques of data use and artificial intelligence such as ontologies, machine learning, sentiment analysis, semantic analysis of social networks, the application of techniques for natural language processing, human-computer interaction models, and natural interface design, among others, help to better understand human behavior. With the recommendations provided by intelligent systems, teachers can timely detect students with problems and carry out a significant intervention, to ensure their inclusion and stimulate the improvement of their performance considering their possibilities, limitations, and preferences, thus reducing school dropout. According to Long et al. (2011), learning analytics are the measurement, collection, analysis, and reporting of data on learners and their contexts, with the purpose of understanding and optimizing learning and the environment in which it takes place. In this sense, they facilitate the processes of monitoring and analysis, prediction and intervention, tutoring, evaluation and feedback, adaptation, personalization, recommendation, and reflection (Chatti et al., 2012).

There are no indications of a systematic adoption within the educational system, of applications based on artificial intelligence for teaching and learning, despite the existence of these applications for years. NúcleoREAA’s members have developed relevant contributions from R & D & I projects (Cervantes et al., 2018; Macarini et al., 2019; Macarini et al., 2020).

An important challenge is to prepare decision makers and teachers for artificial intelligence integrated into education, and at the same time prepare artificial intelligence to understand education, as mentioned by UNESCO in its working document (UNESCO, 2019), contributing to respond to pedagogical problems, and not to deepen them. On the other hand, it is necessary to create new educational possibilities.

Developers of applications of artificial intelligence must participate in an active dialogue with educators, sociologists, educational technologists, pedagogues, communicators, and experts in data privacy, to understand how their solutions benefit educational practices from a human rights and ethical framework perspective.

Developing skills and attitudes to create, connect, and solve problems collaboratively is a process where research plays a highly relevant role. In this context, it is also necessary to promote national policies to explore how the use of big data, open data, federated OER repositories, linked data, and knowledge graphs and the application of artificial intelligence in education can contribute to more effective, better informed, ethical, and inclusive development.

L3) Diversity, equity, and inclusion. Diversity includes considering the different characteristics that make one individual or group different from another, from an equity and inclusion perspective. The concept of equity refers to justice in access, opportunities, and advancement of all people, while seeking to identify and eliminate the barriers that have prevented the full participation of some groups. Inclusion is the act of creating environments in which any individual or group can be and feel welcome, respected, supported, and valued to fully participate. Inclusion in education allows students to learn together respecting different learning processes and valuing diversity.

Ensuring inclusive and equitable quality education is the fourth Sustainable Development Goal (SDG) defined by the United Nations as part of its 2030 Agenda for Sustainable Development (UNESCO, 2019). It is essential to recognize the need for a Diversity, Equity and Inclusion (DEI) approach in the field of open and digital education.

Some of the areas in which the DEI issue has been addressed in open digital education reach areas such as social justice, feminist educational technology, and transversality of neocoloniality and postcoloniality in action frameworks, as well as the development of critical perspectives on openness. Inclusive education, design, and inclusive technologies are areas in which the NúcleoREAA's members have been developing work (Temesio & Motz, 2016; Motz et al., 2019; Oyelere et al., 2020; Rodés & Motz, 2020; Deambrosi et al., 2021).

L4) Critical digital pedagogies. In response to the interruption of face-to-face education due to the pandemic, NúcleoREAA's members participated in many global studies, as Bozkurt et al. (2020). The synthesis of this research suggests how social injustice, inequity, and the digital divide have been exacerbated during the pandemic; the relevance that a pedagogy of care, affection, and empathy acquires in this context, highlighting the importance of open education perspectives, concerns about ethics, surveillance practices, and data privacy. The potential impacts of this transformation, operated by the so-called "great onlining" (Brown et al., 2020), generate concern regarding the way that these remote teaching experiences in the emergency lead to uncritical and dubious quality models that affect in a negative way the current and prospective scenario of education, and particularly in the influence on the digital transformation of universities, addressing digital literacy and the transformation of the curriculum, as key dimensions of the digital university committed to social justice (Johnston et al., 2018). In this framework, teaching teams and decision makers need institutional support and teacher professional development strategies to face this enormous challenge, in order to mitigate the potential effects on the quality of teaching and favor that this massive and emergency experience allows to lay the foundations of sustainable models, instead of a massive digital colonization by the big platforms.

Critical digital pedagogy (Stommel et al., 2020) constitutes a central emancipatory approach, supporting the redesign of technological spaces and environments for teaching and learning from a radical understanding of digital, pedagogical, and social relationships, expanding the possibilities of democratization of digital education as a public good.

Addressing these highly complex issues involves significant challenges. Integrate the ethical perspective of care (Barnes et al., 2015) as a fundamental dimension of teaching practice (Noddings, 2012; Adams & Rose, 2014) and the consideration of the teaching function as an experience of care, analyzing dimensions of diversity (power, class, ethnicity, gender, culture, and access), in order to minimize inequity and maximize the degree to which relationships are reciprocal and oriented toward social justice (Rolón-Dow, 2005).

The context described makes it necessary to generate new research to examine, in detail, the effects and consequences of the expansion and incorporation of digital technologies and media in educational systems, institutions, and practices. Although these are not new problems generated exclusively by the pandemic, they are being experienced mainly by educators and students at all educational levels (Williamson et al., 2020). In this sense, this line aims to advance toward critical and innovative teaching practices, giving continuity to the research developed by NúcleoREAA's members on pedagogical teaching strategies in digital environments, pedagogical models and architectures, symbolic and practical appropriation of digital technologies by teachers and students, creation of open educational resources, and design and redesign of teaching in distance education settings (Pérez et al., 2017; Rodés et al., 2018; Czerwonogora & Rodés, 2019a, 2019b). Of particular interest are the professional development processes of university teachers, whose academic profile associated with their disciplinary specialty does not usually include pedagogical-didactic training.

Milestones in Building Inclusive Education

Regarding the trajectory of the NúcleoREAA in building inclusive education, integrating networks, and provoking synergies between academic and nonacademic spaces, nationally and internationally was the first milestone. The first Technical Report (2017) highlights the area of Repositories and Open and Accessible Educational Resources as eminently interdisciplinary and refers to the comprehensive and innovative approach that this convergence made possible. It also points out the potential to contribute to the theoretical-methodological construction of a field of theories and practices developed around the transdisciplinary articulation of still emerging and disruptive fields, in their disciplines of origin.

The context described a second milestone of its subsequent development was deepening and adding disciplinary fields and facilitating spaces for innovation and development that have been able to integrate a variety of actors. It is worth highlighting in this panoramic vision to the work of the Nucleus: Open Educational Resources as a topic, object of study, and scope of performance; Accessibility of OER, as a concept with multiple implications: its construction, availability, use, and institutional context; collaborative processes, both from the theoretical depth of the concept, and from the perspective of social and community action, as well as from a way of conceiving collaborative work in digital environments; learning analytics, data collection, and analysis process on individual student interaction with online learning activities and their contributions to pedagogy and didactics; and finally, the legal framework to address the implications of information management and its ethical challenges regarding security, people's rights, individual and institutional freedoms, and responsibilities.

The continuity and profusion in the production of the NúcleoREAA in research, teaching (in continuous education, undergraduate, postgraduate, and open courses), and third mission has strengthened its presence and recognition at the national and international level, linked to the relevance and timeliness of its topics and its condition of convening space between academic, civil society, and governmental sectors. On the other hand, NúcleoREAA participated, internationally, in various conferences in the area (LACLO, SIIE, CACIC, OEGlobal, and OER). Also noteworthy is the joint activity with the UNESCO Chair in OER, Brazil, the UNESCO/ICDE Chair in OER, Cánada, and the UNESCO Chair in Open Educational Movement for Latin America, México. During the last decade, NúcleoREAA expanded its national and international networks, by developing many research projects that are the core of its actions. The most important projects in terms of impacts are presented below, in Table 1.

Milestones of the last period were the approval and start of the implementation of the International Interinstitutional PhD Program in Informatics in Education, in collaboration between Universidade Federal de Rio Grande do Sul (UFRGS), Brasil,

Table 1 Major research projects

Project	Description	Founder	Year
ESVIAL	Virtual Inclusive Higher Education for Latin America	Alfa III Program of the European Union	2011–2015
LATIN	Latin American Initiative of Open Textbook	Alfa III Program of the European Union	2011–2015
REMAR	Network for the accessibility and collaborative generation of open educational resources	PASEM-MERCOSUR	2013–2015
RIURE	Ibero-american Network for the usability of educational repositories	CYTED	2013–2016
BIDYA	Digital and Accessible Library	FRIDA-IDRC	2016–2017
AREA	Use of the Ceibal Repository of Open Educational Resources by the Teacher Network	National Research and Innovation Agency (ANII)	2016–2017
DIIA	Discovery of Interactions that Impact in Learning	National Research and Innovation Agency (ANII)	2017–2018
PREDICTIVE MODELS	Predictive models for the determination of academic risk in education	National Research and Innovation Agency (ANII)	2017–2018
PRAXIS (I&II)	Pedagogical-didactic training in technologies and teaching practice	National Research and Innovation Agency (ANII)	2017–2020
SELI	Smart Ecosystem for Learning and Inclusion	ERANET-LAC National Research and Innovation Agency (ANII)	2018–2021

and Universidad de la República (UDELAR) and the approval of the Unesco Chair on Open Education within the framework of the NúcleoREAA.

Finally, we highlight two inclusive innovation projects that were developed during the last period that are milestones in the consolidation of our work in inclusive education. At the national level, it is the second phase of the BIDYA project funded by the National Research and Innovation Agency (ANII), in its Inclusive Innovation line. At the international level, the Smart Ecosystems for Learning and Inclusion (SELI) project stands out, funded through an ERANet-LAC call.

Following, we describe the most important developments made within these two projects, and their relevance as a summary of our comprehensive approach to educational and digital inclusion.

Accessible Digital Library: Digitization of Libraries Within the Framework of Compliance with the Marrakesh Treaty

The project aimed to intervene on some of the factors involved in the educational trajectories of people with visual disabilities, in order to offer tools that favor their integration and permanence in the formal educational system, guaranteeing equal opportunities.

In 2016, the Digital and Accessible Library project (BIDYA), presented by the NúcleoREAA and the National Union of the Blinders of Uruguay (UNCU) to the FRIDA-IDRC Program, was one of the ten innovative projects in Latin America and the Caribbean financed that year. This innovative project, which ended in July 2017, set out to generate a repository of educational materials accessible to people who are blind or have low vision, the Accessible Digital Library (BIDYA), at Universidad de la República.

During the implementation, more than 500 textbooks and study materials for the K12 curriculum in Uruguay were selected, digitized, adapted, and delivered in a repository. These documents can be read by screen readers suitable for the target audience. The results of this project were tested, improved, and approved by a group of people who are blind or with low vision. As a result, the launch of the Accessible Digital Library was completed by generating an accessible web portal (http://www.bibliotecaaccesible.ei.udelar.edu.uy/) and the publication of the resources in a special collection within COLIBRÍ – Institutional Repository of the UdelaR (https://www.colibri.udelar.edu.uy/jspui/handle/20.500.12008/9313). Another result of the project was the development of training and awareness-raising activities aimed at students, teachers, librarians, educational authorities, and the general population.

The project "Accessible Digital Library: Digitization of libraries within the framework of the compliance with the Marrakesh Treaty" is the continuity and expansion of the Digital and Accessible Library (BIDYA) project. It is aimed at the expansion and consolidation of one of the first successful experiences of implementation of the Marrakesh Treaty worldwide and the first in Latin America.

The project expanded the impact and scope of this digital library from digitization, availability in accessible format, and publication in the Digital Accessible

Library of corresponding educational resources at the university level at UdelaR, in which blind or low-vision people are studying.

Among the results achieved, the following stand out: 1) the expansion of the impact and scope of the Accessible Digital Library to the entire National Education System; 2) the generation of methodological guides for accessible digitization, web accessibility of repositories and digital libraries, information literacy for blind or low vision users, and strategies for the adoption of accessible digital libraries; 4) the promotion of its sustainability and replication in all libraries and national educational institutions covered by the Marrakesh Treaty, through the implementation of various training courses and activities for undergraduate, graduate, and graduate students; 5) the creation of the BIDYA Network, composed by organizations of civil society, activists for inclusive education, librarians, and other relevant stakeholders; 6) promoting the implementation of the Marrakesh Treaty in Uruguay by establishing joint lines of work with the National Library, the Copyright Council of the Ministry of Education, and the Monitoring Commission of the Marrakesh Treaty in Uruguay; and 7) the promotion of international collaboration for the promotion of accessible digital libraries at national and foreign educational institutions through participation in the creation and promotion of the Observatory of the Marrakesh Treaty in Latin America.

Smart Ecosystems for Learning and Inclusion (SELI)

The project is funded through the call, ERANet-LAC, which aims to strengthen international cooperation in research and innovation between agents of the European Union (EU) and those of Latin America and the Caribbean (LAC). Financing in Uruguay is in charge of the National Research and Innovation Agency (ANII).

The project addresses the issue of digital inclusion and accessibility of education for disadvantaged groups, improving the digital skills of teachers in the regions involved. The three focus areas are: 1) new pedagogies and methods; 2) new learning environments; and 3) digital training for educators. The project provides activities for teachers and students from participating countries with little access to educational technologies, collaborating with training and inclusion.

Many causes are responsible for the global lack of inclusion of people with disabilities: inadequate legislation, policies, and strategies; the lack of service provision; negative attitudes and discrimination; the lack of accessibility; inadequate funding; and many others. Considering this worldwide challenge, SELI project is designed to answer needs in regions and countries based on current conditions of unemployment, homelessness, street children, low education level of the disabled population, migrants, etc.

The SELI project has implemented workshops and focus group sessions with stakeholders and target groups (on the educational side with schools, social centers, and HEIs, on the technological side with ICT experts, and in the business part with entrepreneurs, companies, and SMEs); to discover needs and requirements for emerging pedagogies, methods, and technologies (such as blockchain, global sharing pedagogy, e-inclusion, e-accessibility, digital storytelling, flipped learning, and educational games).

The target groups are educators (higher education teachers, preservice teachers, and trainers in the social service sectors), entrepreneurs, and innovators in both the public and private sectors. Students, young people, the unemployed, the disabled, the elderly, migrants, and people living in remote areas in Europe and the LAC are its final beneficiaries.

In addressing the lack of accessibility to education, inclusive practices, and ICT technologies, the project fosters knowledge transfer and adapts pedagogical, scientific, and technical solutions for the specific problems of each country of the consortium. The collaborative approach means that the project addresses the wide scope of actors involved in the issue of improved education, inclusion, and accessibility through ICT.

Main achievements of the project include 1) learning environments, content, and services within the same architecture; 2) the development of methodologies and strategies (Porta et al., 2020).

Regarding technologies, contents, and services, SELI learning platform provides the opportunity to create courses for various types of disabilities, taking into consideration accessibility standards, interaction between students, and stimulating the creativity of tutors and students. The infrastructure provided by the SELI project is based on a Blockchain architecture and on having a set of microservices that can be incrementally coupled to offer different functionalities, one of which is learning analytics. Among the contents, courses are designed for students, young people, the unemployed, the disabled, elderly, migrants, and people living in remote areas in Europe and Latin America.

SELI project involved several piloting initiatives, and communities of practice. For example, workshops were held with teachers in Brazil, the Dominican Republic, Uruguay, Poland, and Turkey. This allowed the project team to explore the views of participants on inclusion related to their profession. Pilot tests were carried out in all partner countries, allowing the project team to observe the teachers' perception of the usability of the SELI platform, more specifically using authoring and digital storytelling tools. These observations led to an improved second version of the SELI learning platform that involved the development of a new authoring tool based on the ADDIE model (Analysis, Design, Development, Implementation, and Evaluation) and a new digital storytelling. Both the new authoring tool and the two versions of the digital storytelling tools provided more inclusive solutions targeting more diverse users. For example, two digital storytelling tools are available to facilitate users who require more guidance in visual or auditory communication. In this way, the digital stories on the SELI learning platform have the possibility of empowering users by giving a voice to the most diverse, so that they can be heard in the community.

The authorship tool based on the ADDIE model allows teachers to identify inclusion goals such as cognitive disabilities, diversity of abilities, and hearing and visual impairments when creating courses. This identification allows them to use more specific tools depending on the needs of the target group.

SELI is one of the many solutions that are part of the activities aimed at positive change, resulting from the diagnosis of individual and systemic resources, conceptual work, cooperation of representatives of the education sector with the technical sector (IT), and the testing and implementation of an innovative digital learning environment. Despite the diversity of partners, the objective is coherent and prioritized.

The transformation of education with digital support is currently not an idealistic assumption, but a goal of concrete and coherent actions. Undoubtedly, the solutions applied in the project aimed to contribute to increasing the effectiveness of learning and teaching and the attractiveness of group activities. Today's students and teachers are a completely different generation than their peers of decades ago. They are a generation that recognizes and appreciates the potential of diversity and digital media.

The nonstandard cooperation of professionals, scientists, engineers, and programmers shows that just going beyond typical schemes allows quality and creativeness. Regardless of technical achievements, the SELI project has created an opportunity to engage a large community of researchers and developers in an interdisciplinary process. This has been an opportunity to learn the languages and perspectives of others on inclusive technology and education.

The Way Forward

The work carried out in the last decade has allowed us to build a comprehensive, intersectoral, and interdisciplinary perspective, critical and propositional, which has contributed to the development of inclusive education in Uruguay and in Latin America. This theoretical-methodological construction, which puts people at the center, has the vocation of deepening, calling for more actors to join, in order to expand the concentric circles of influence in educational transformation.

The way forward is one of considerable complexity. The national and global economic crisis, and the conjuncture of educational continuity in the Covid-19 crisis has deepened educational gaps, going back decades in the educational inclusion work carried out by countries and organizations.

The influence of the large platforms and the digital colonization of the educational and social sphere leads us toward the challenge of building with others a decolonial agenda that allows maintaining and deepening digital citizenship, technological sovereignty, and educational inclusion. We invite those who want to join the challenge.

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Improving Inclusive Pedagogical Competences of Educators While Facing Pandemic Restrictions

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Karel Van Isacker, Petya Grudeva, and Maria Goranova

Contents

Abstract

Since March 2020, the COVID-19 pandemic impacted education worldwide, bringing new perspectives as well as many challenges in daily and professional practices. The education system as well as the students, with and without disabilities, were and are still affected by the "new normal" of the pandemic era. Schools and teachers had to change their strategies in order to adapt their curriculum and approaches to the need for remote education. Remote courses, online practices,

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and virtual classes brought new opportunities but equally challenges for inclusive education.

For students with disabilities and special learning needs, moving to distance learning has posed opportunities, especially for those that benefitted from remote teaching. However, additional obstacles emerged for others, including barriers to technology engagement, limited access to instructional resources and individualized learning interventions, and the lack of social interactions.

In reaction to these challenges, many teachers have quickly adapted their practice and developed creative approaches to delivering comprehensive education to all students. However, gaps exist, resulting in obstacles for students with disabilities, while equally offering opportunities for further training and empowerment of inclusive educational practices.

In this chapter, a clear overview of the impact of the pandemic on inclusive education is raised, how the online teaching practice offers solutions but equally faces challenges, while this research also looks at recommendations to enrich the teacher's competencies on how to address these challenges.

Keywords

Inclusive pedagogy · Inclusive education · Inclusive education during Covid-19 · Inclusive education in the crisis period

Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
IPAA	Inclusive Pedagogical Approach in Action
MOOC	Massive Open Online Courses
OER	Open Educational Resources
PC/TV	Personal Computer/Television
UN	United Nations
VET	Vocational Education and Training

Introduction

The COVID-19 pandemic has caused the biggest threat ever to school systems, worldwide, affecting nearly 1,6 billion students in over 190 countries across all continents. School and other learning premises closures have affected 94% of the world's student population, rising to 99,9% in low- and lower-middle-income countries (UN, 2020).

Political, social, sociological, and financial infrastructures have always been difficult to navigate when it comes to inclusive education trips. As this chapter shows, the Covid-19 period merely enhanced the constraints and obstacles associated with inclusive education mandates. This has mostly been the case in terms of access to technology, inaccessible content, a lack of proper teacher training, rules that ignore the demands of various student needs that have risen as a result of the "new normal" of the COVID-19 era, etc.

This interruption has impacted students and instructors globally, from elementary through secondary schools, technical and vocational education and training colleges, universities, adult learning, and skill acquisition institutions (UN, 2020). Due to enforced seclusion and parents being overburdened with additional obligations that would have been carried by the educational institutions instead, it has also frequently had a severe influence on family life.

Because of the flexibility of e-learning in terms of delivering education and gaining access to materials, which involves teaching remotely and on digital platforms (Bakia et al., 2012), schools, instructors, families, and students were forced to adopt new methods to learning. The epidemic has forcefully enhanced the e-learning uptake in 2020, and it is projected to remain at a high level in the years to come. In the previous 20 years, e-learning only slowly took off and encountered several obstacles (Removing Barriers to Online Learning Through a Teaching and Learning Lens, ABLE Research Consultants, 2020).

COVID-19 Impact

At the beginning of the outbreak, no country had a universal digital curriculum for teaching and learning in place. This merely proves the efforts that governments and schools had to take to rapidly move toward distance learning, thus ensuring continuity of learning, but equally resulting in several problems for disadvantaged children (mainly children with disabilities and socially disadvantaged children).

First of all, remote education requires students with disabilities to have all needed technical equipment available at home. This ranges from assistive technologies to fast Internet access, the availability of a PC/TV/laptop/smartphone depending on the channel used by their educational institute to offer teaching, etc. This requires an investment by families, whereby the impact poverty has on (special education) students, which has been thoroughly described in various studies, should not be ignored (Enwefa et al., 2006). Some countries (Belgium) have identified this negative impact and have gathered many 1000s of laptops to ensure everyone can follow lessons. In other countries like Bulgaria, the focus has been on trying to teach also using smartphones, etc. to overcome financial barriers.

Online courses with a digital component rely on students' navigational and digital skills. However, learning management systems typically provide difficulties for students who have print disabilities or other physical, cognitive, or other limitations. Prior to COVID-19, schools already lacked completely accessible online teaching strategies as well as precise instructions on what accessibility actually meant. Here is a little illustration to help: When schools do invest in online learning resources that vendors claim to be accessible, they frequently discover that they fall short of even the most basic requirements for kids with visual impairments. Not all e-texts, for instance, are keyboard friendly or accessible, and others may have a proprietary format that makes it difficult for people to use or access if they have visual, motor, physical, or sensory impairments. For people who have other visual issues, dynamic e-learning content, such as additions to e-texts like movies and images that change when a user scrolls over or clicks on different portions, might be difficult.

Online education cannot replace the value of body language or account for all variations in educational approaches. Hence, teachers should modify their lectures for the online setting rather than merely transferring what was typically delivered in the old manner online (Sun et al., 2020).

Huang et al. (2020) identified seven important aspects that stand at the basis of online education and that have an essential role in optimizing learning in special circumstances like the ones created by the Corona virus pandemic (Huang et al., 2020). These aspects involve the following:

- Maintaining and expanding Internet infrastructure to prevent disruptions, particularly during video conferences.
- Using user-friendly technologies to assist students in assimilation and comprehension of knowledge.
- Providing dependable, engaging, and diversified electronic resources.
- Using social media to create online groups for kids to decrease feelings of loneliness.
- Using many successful strategies such as discussions or discovery and experience-based learning.
- Offering services that assist students and instructors in learning about the most recent policies implemented by educational institutions and the government, as well as fostering collaboration among these institutions.

These concerns, however, overlook the impact on kids with impairments who may require special assistance. While chat settings may technically allow (a)synchronous communication, chat styles might differ, appear discordant and scary, and hence risk alienating or marginalizing students. Children on the autistic spectrum who rely heavily on established daily rhythms and specialized interaction models may face crises and meltdowns when these patterns are disrupted by distant instruction. According to research, one of the most important factors influencing e-learning system adoption is self-efficacy (Almaiah et al., 2020). And developing self-efficacy is not always easy for students with impairments.

Teachers and students continue to face challenges in the field of inclusive education. Additionally, the pandemic process brought up new challenges that emerged throughout the epidemic terms, as well as increased the intensity of these issues. Teachers and youth workers who want to maintain inclusive education must be aware about and taught in accordance with these recently developed conditions. Along with updating their methods and course materials, they should also refresh their knowledge. The implications of COVID-19 on inclusive education will be discussed in the next section, along with potential challenges and solutions.

Inclusive Education

Inclusive education systems value the unique contributions that students from all backgrounds make in the classroom and allow different groups to thrive alongside one another, benefiting everyone (Inclusive Education, UNICEF). Children with disabilities are given opportunities for meaningful learning.

Inclusive education seeks to guarantee that all students have an equal chance to attend school, learn, and develop the skills necessary for success. In order to achieve inclusive education, all students must be placed in the same classes and educational institutions (primary and secondary education, higher education, and adult and VET education). It entails providing meaningful learning resources to persons who have historically been marginalized: pupils with impairments.

An inclusive curriculum promotes students from diverse backgrounds to learn and thrive alongside one another, which benefits everyone (Unicef). It implies that kids with disabilities are as entitled to and capable of obtaining a foundational education as any other student. Students may work in a more free setting without feeling rushed or restricted thanks to this.

The United Nations mentioned inclusive education in their UN Convention on the Rights of Persons with Disabilities. According to Article 24, “States Parties recognise the right of persons with disabilities to education... States Parties shall ensure an inclusive education system at all levels and lifelong learning...” (UN Convention on the Rights of Persons with Disabilities).

Students from different backgrounds and ability levels might learn a lot when they work together on an inclusive curriculum. They would be able to develop better problem-solving skills and understand the value of collaboration and teamwork. Academically, socially, and in terms of their ability to communicate and interact with others, students with impairments would benefit. They would feel like a common person in society and be treated accordingly. Peers of the pupils who do not have impairments would foster a positive and sympathetic attitude toward these individuals. By supporting their classmates, students would extend their perspectives, embrace differences, develop their skills, and acquire particular fundamental human qualities (Fostering Inclusive Education in Times Covid-19). Participating in a peer group should strengthen social interactions, foster peer solidarity and peer learning, and psychologically excite students with and without impairments, reflecting this in their academic results. Furthermore, during pandemics, all pupils with and without impairments are expected to be able to study and enroll in age-appropriate regular classes. They should have access to educational programs and teaching that are adapted to their individual need (UN, 2020). Children should participate in cocurricular and extracurricular activities, and they should profit from collaboration and participation at home, in school, and in the community. For example, most students are expected to attend various shifts of online and in-person classes. They had to plan their timetable around COVID-19 measurements. They were supposed to develop their IT abilities during the online learning process, so they could participate in classes, turn in assignments, and even take tests online.

However, as will be shown in the next section, these objectives do not always match up with reality.

Inclusive Education in Pandemic Crisis with Lockdowns

Schools had to modify their practices and timetables during the Covid-19 era in order to keep pupils safe as they continued their education. All schoolchildren must now complete digital education due to the global pandemic problem, whether they are ready or not. There are still numerous difficulties to be solved.

New Normal of the Pandemic Era

The pandemic has added little to new curriculums and education in general; instead, it has accelerated what may be called the technologization of previously existing trends. The pandemic ushers in a "new" normal in which digitization imposes new ways of working and studying while pushing education much further toward technologization, a process that had already started as parts of the teaching of the twenty-first century (15 Characteristics of a 21st-Century Teacher), whereby today's tools and technology enter the classroom.

The curriculum for COVID-19 has been relocated online, physically separating the students from one another, from their professors, and especially from the dialogical experiences that might take place in classrooms. While online learning is the likely solution to school closures, other writers believe that education channels are increasingly expanding and that learning awareness is being reduced to data to be transmitted (Pacheco, 2020).

There is a significant risk that children with disabilities who were enrolled in school before the crisis may not return. They may feel less included in the class setting and isolated during online schooling. On the other hand, because online schooling does not take much physical work, kids may be reluctant to leave their newly found comfort zone after the COVID-19 time. As a result, the crisis may intensify the alienation and isolation that existed before the crisis. Parents of children with disabilities can worry about the health hazards associated with their children's return to school.

It is uncertain if online learning would continue after the epidemic and how such a shift will effect global education given the quick shift away from the classroom in many areas of the world.

Numerous preexisting patterns and trends have been highlighted by COVID-19. On the one hand, this research has revealed a number of flaws and vulnerabilities, such as the accentuation of inequality, general erosion of consistency and quality of informational education, and how ill-prepared the educational system was for a significant transition from traditional classroom instruction to digital and distance learning. However, certain beneficial aspects of the society have also started to stand out more and more. The numerous educators, families, and children who are collaborating to provide extraordinary learning opportunities exhibit cooperation, a firm, resilient response to challenges, as well as resourcefulness, passion, and creativity (UNESCO, 2020).

(Not) Challenging for Pupils/Students with Disabilities

Remote education is not a new term in education. It became an indispensable practice during the pandemic time as part of the imposed lockdowns worldwide. Remote education opened a new page in inclusive education not only with its advantages, but also its disadvantages. These will be addressed in the next sections.

Advantages of Remote Education

The fundamental benefit of remote learning is that it promotes the health and safety of others while helping to keep students and teachers on the job.

Students with limited mobility can escape the everyday difficulties of travel and navigating a classroom with the help of remote education. Instead, individuals can gain from a personalized study place that is optimized for them and allows for their range of motion.

Students may now actively participate in class discussions and follow their courses online thanks to technological advancements. Most of what students accomplish in the classroom can now be done virtually thanks to virtual classrooms. Additionally, the potential accessibility of education is increased by the digitalization of education. When they choose, students can download course materials and replay recorded lectures. Communicating through forums and social media relieves the strain of communicating with others, particularly for those who are shy about speaking in front of a group or who require time to gather their views. Remote education includes a range of tools, platforms, and software that teachers may use with their courses to boost their students' attention.

Students who are unable to use their hands and feet due to cerebral palsy, muscular dystrophy, or other disabilities are frequently habituated to dictating text or email using voice-activated applications or speech-recognition systems such as Dragon NaturallySpeaking. Many people also utilize eye-tracking technology such as Tobii (which uses the iris to issue commands to a computer that then speaks for the user). Students with mental or psychological problems, post-traumatic stress disorder, or cyclical mood disorders have the freedom to plan their study schedules around changes in receptivity.

Students with Asperger's syndrome and other autism spectrum disorders, as well as those who struggle socially in general, can work in more familiar, relaxed environments, such as at home, rather than in huge classroom settings. A side note must be noted, too – confinements also mess with a schedule that autistic youngsters were used to.

Students may be relieved of time constraints through online programs. Students who struggle with learning problems such as attention deficit hyperactivity disorder

(ADHD), dyslexia, visual processing disorder, or dysgraphia should pay close attention to this. The typical classroom's potential stressors, auditory or visual overstimuli, and diversions are also avoided. Students can examine materials as much as necessary while working at home at their own speed. They can even edit digital text to comprehend knowledge.

Students with hearing impairments have options thanks to digitized course materials, subtitled lectures (rare), and asynchronous communications.

Handheld digital audio recorders and note-taking programs like AudioNote can help students who have poor eyesight or no vision record lectures in class. Similarly, screen reader software, such as the open-source NVDA, outputs text-to-speech or feeds a Braille display, the fact that the source information was presented in an accessible style and fulfills, for example, WCAG 2.0 guidelines.

Disadvantages of Remote Education

Despite these benefits, there are a few drawbacks to remote learning that should be taken into account. The nonexhaustive analysis that follows tries to highlight the most glaring drawbacks of distance learning.

The effects of poverty on students are already addressed, and this is especially true for students with disabilities who frequently need to purchase expensive supporting technology and software (appropriate and necessary devices to connect and learn, such as assistive technologies, whether operated via laptops, tablets, smartphones, reliable yet affordable home Internet access). Then there are the many forms of educational resources, ranging from individualized lesson plans for teachers to fully scoped and sequenced student online textbooks, OERs, and MOOCs. Finally, it should not be overlooked that formal training and informal practice to acquire and master digital technologies will be necessary in many circumstances, both for students and instructors, as well as technical assistance (Examining 5 Key Costs of PreK-12 Distance Learning, 2020).

Implementing digital-based online programs assumes that students can browse the information. However, some learning management systems (LMS) create hurdles for students by failing to provide the necessary accessible interfaces or failing to adhere to an uniform layout. Even with a fully accessible LMS, an instructor or course developer can easily generate inaccessible pages within the course that lack correct heading structure or feature images without alt text. By submitting inaccessible PDFs or other digital documents, films without subtitles or audio explanations, and other inaccessible course materials, they can also violate accessibility. Equally, by selecting to utilize a plug-in that was not created with accessibility in mind, a teacher or course creator might make an otherwise accessible course less accessible (How do learning management systems differ on accessibility?).

Because of the aforementioned LMS restrictions, many schools do not have completely accessible online resources. In addition, it is possible that the people who designed the courses themselves did not have clear instructions on what accessibility meant and how to include it into their materials. There are several content suppliers who publish nonaccessible electronic editions of their textbooks for students with special needs. A way to remediate this issue is by annotation of these inaccessible documents. A good example is the ADIBib program. A PDF of educational material that was not created in an accessible format is being manually annotated in Belgium as part of Eureka's ADIBib program (Adiboeken En Voorlees-software Voor leerlingen met een lees- of schrijfbeperking), thus to make it accessible for screen reader software. Unfortunately, lockdowns that come out of nowhere cause clear bottleneck issues since the demand for such customized accessibility cannot be met in a timely manner.

Those with impaired vision or color blindness may struggle to see particular colors, typefaces, and formats. Dynamic e-learning information, such as e-text features, movies, and images that change as a user scrolls over or clicks on different portions, might be difficult for persons who have other visual issues.

Screen readers and voice transcribers, for example, may demand more bandwidth than students have at home. Punctuation varies from one screen reader to the next, and not all marks translate. Keeping up with advancements also necessitates regular software updates, which may be pricey with specialized screen readers. As a result, open source solutions such as NVDA are becoming more popular (JISC TechDis' free and open source software listing).

Challenges and Solutions

COVID-19 pushed Internet as the primary medium for education. To ensure the well-being of their pupils, teachers moved their lessons online. As previously noted, several difficulties emerged throughout the lengthy periods of distance instruction, ranging from infrastructural to psychological to educational in character (shown in Table 1).

In the context of the MyHub project (https://handbook.inclusion-hub.eu/handbook/10/10_1?lang=en. Accessed 05 Jan 2022), some indicative challenges and solutions have been identified regarding online education for students with disabilities, in a European context. They are listed in Table 2.

Table 1 Challenges faced

Challenge	Examples
Infrastructural	Lack of internet connection, lack of devices, and lack of online resources/systems
Psychological	Anxiety, depression, lack of adaptation, and isolation (Matthew et al., 2021)
Educational	Inadequate education, learning loss, lack of evaluation, and lack of inclusion/engagement in the class
Various fears	Risk to be contaminated, disorientating time of inactivity, and de-socialization

Table 2 Challenges and solutions related to online education

Challenge	Solution
Personal support in the classroom is missing	Remote assistance is being provided by the same persons that normally provided the support in the class (Example from Italy)
Training material and platforms not accessible	Zoom is an easy, affordable, and accessible virtual meeting tool (https://zoom.us/accessibility. Accessed 12 Apr 2021) for students with visual impairments, while homework assignments in the form of Microsoft Word documents and Google Docs can be read by screen-reading technology. It does however require that accessibility guidelines are applied when creating the learning materials, guidelines which are freely available online and provided by Microsoft, Open/Libre Office, etc. (https://www.microsoft.com/en-us/accessibility/resources, https://www.openoffice.org/ui/accessibility/, https://www.libreoffice.org/get-help/accessibility/. Accessed 12 Apr 2021)
Parents are in a panic about how their child will be able to follow the lessons	Teachers need to talk with the parents and children to identify what their specific needs are. Teachers need to look at it as an opportunity to think creatively and think outside the box to figure out what can be done for the particular student who is impacted
How do I as a teacher adjust my course for remote and accessible education?	Four main tips (https://svp.umd.edu/keepteaching, Accessed 12 Apr 2021): Keep it simple – do not try anything new or complex if you do not have to Do not try to be perfect – this is a significant challenge for everyone. Things will not go as planned. The technology may falter. Students may have access challenges Be honest, transparent, and respectful – communicate with your students about the challenges. Let them know what you are trying to do and ask for help, from them, from your colleagues Review and be sensitive to the required privacy and security settings
Staff is not aware of accessibility guidelines for their teaching material	Resources should be made available to teachers, children, and parents that lower the barriers toward participating in online courses. An extensive guide on accessibility, especially how to accommodate students online, is needed Free online resources (https://www.microsoft.com/en-us/accessibility/resources, https://www.openoffice.org/ui/accessibility/, https://www.libreoffice.org/get-help/accessibility/. Accessed 12 Apr 2021) can be very helpful

Post-COVID-19: How the Educational System May Adapt Toward an Inclusive Pedagogical Approach

The digital tools that are common to the teaching profession are the ones that are the focus of teacher education (e.g., the Digital Competence Framework for Educators – DigCompEdu framework (https://ec.europa.eu/jrc/en/digcompedu, https://ec.europa.eu/jrc/en/publication/eur-scientific-and-technical-research-reports/european-framework-digital-competence-educators-digcompedu, Accessed 12 Apr 2021)). The need for teacher education to be responsive to the more distinctive disciplinary practices and traits that characterize each given school topic, particularly those practices that may address the issues encountered in a COVID-19-racked educational system throughout Europe, is equally important. This is especially important when considering those most impacted by the pandemic's impact on education: children with special needs who become disoriented in the new teaching reality (support teachers who are not present in person, different daily structure, etc.) as well as those who do not have the financial means to participate in online learning (lack of hardware, software). So yet, limited steps have been taken across Europe, and they are not harmonized.

There is an evident need for educators to have digital and inclusive pedagogical abilities where inclusive learning activities are addressed, where scientific disciplines, professional disciplines (pedagogy and subject didactics), and inclusive practices all contribute to a cohesive whole. Inclusive learning environments and learning pathways are also included in this. Generic, inclusive, and subject-specific features of the technologies combine and are operationalized in the design to provide a truly inclusive educational practice.

The teacher's abilities to translate traditional lesson delivery into digital content – including what pedagogic strategies to utilize, what exercises would be appropriate, and what are the (more accessible, open-source) solutions they may use – are equally crucial.

As a result, a model for integrating digital and accessible resources into teachers' pedagogical practice can take place with two dimensions: one dealing with the kinds of factors that influence teachers' adoption of digital content, and the other with the traits of different stakeholders and the nature of digital curriculum resources (the content) and supporting technology (the tools).

As a result, inclusive pedagogy was developed. It is a pedagogical approach that strives to improve learning chances for all students in order to decrease educational disparities. Its purpose is to improve traditional education by removing practical uncertainty. It was developed as a consequence of research aimed at recognizing the qualities of teachers who are willing to connect with a wide range of pupils in order to ensure outstanding academic achievement for all students, particularly those who require more help (Florian, 2015).

The Inclusive Pedagogical Approach in Action (IPAA) framework (Spratt & Florian, 2015) can thus serve as a support mechanism for teachers to develop responses to individual differences in ways that do not marginalize any learner (Spratt & Florian, 2015), while also taking into account the challenges that have arisen as a result of forced lockdowns in educational settings and their effects on students with special needs. The IPAA philosophy replaces deterministic ideas about children's abilities and cognitive growth with the idea of transformability. This idea helps inclusive professionals behave, feel, and think like inclusive instructors while also demonstrating inclusive teaching. It has been proposed that a deeper comprehension of IPAA can assist instructors in moving away from dividing kids into groups based on their impairments and toward seeing them as capable learners (Spratt & Florian, 2014).

Children with special educational needs can convert learning and developmental risks into positive outcomes by properly using the IPAA framework. This is

Table 3 Summary of IPAA. (Adapted from Spratt & Florian, 2014, 2015)

Principles/underlying assumptions	Associated concepts/actions	Key challenges
Difference must be accounted for as an essential aspect of human development in any conceptualization of learning	Replacing deterministic views of ability with a concept of transformability	"Bell-curve thinking" and notions of fixed ability still underpin the structure of schooling
Teachers must believe (can be convinced) they are qualified/capable of teaching all children	Demonstrating how the difficulties students experience in learning can be considered dilemmas for teaching rather than problems within the student	The identification of difficulties in learning and the associated focus on what the learner cannot do often put a ceiling on learning and achievement. Teachers must change their beliefs that some children are not their responsibility
The profession must continually develop creative new ways of working with others	Modeling (creative new) ways of working with and through others	Changing the way of thinking about inclusion (from "most" and "some" to everybody)

especially relevant since inclusive pedagogy maintains that every child's learning capacity is malleable: What instructors do (or do not do) now can impact a child's learning capacity in the future (Florian & Black-Hawkins, 2011). The IPAA framework is summarized in Table 3.

The IPAA framework views every child as a "active meaning-maker, who uses her/his personal and social resources to make sense of the world as she/he experiences" while learning from inclusive teachers (Nind et al., 2014). It demonstrates a deliberate effort to enhance the learning environment for all children, as opposed to focusing on the shortcomings or needs of certain kids (Boettcher, 2007).

Engaging educators in conscious reflection on their own practice may significantly advance their knowledge, and being, and improve the way they instruct all students to get the most out of their educational opportunities (Dall'Alba, 2004; Florian, 2009).

Participants can move away from deterministic views of ability with the help of the IPAA framework (Brennan et al., 2019). Additionally, it could result in the much-needed paradigm change in inclusive educational strategies. Furthermore, IPAA can assist instructors and practitioners in increasing their potential and performance when teaching online. New obstacles and possibilities that arose throughout the distant education process should be addressed, and solutions to assist instructors should be developed, combining this with the IPAA approach as applied to online learning practices.

Conclusion

The COVID-19 epidemic has forced the emergence of online learning in a way that has never before been placed onto the educational community. But in order to guarantee that the requirements of children with special education needs are also satisfied, assistance for teachers and schools in implementing digital inclusive education preparation, encompassing also inclusive pedagogy methods, will be required.

By accomplishing this, the post-COVID-19 period will be successfully organized, and an inclusive school year will be realized. The importance of this is increased by the likelihood that many kids' everyday school experiences will increasingly involve remote teaching and learning. From the numerous examples, it became evident that the issues are not only digital in nature, but also related to the participation of instructors and children with special education needs in educational settings that have significantly transformed, essentially overnight.

It is therefore necessary not only to rely on existing practices, such as various accessibility guidelines for online/offline teaching material, but also to improve current pedagogical approaches and embrace and update, for example, the IAAP framework, thereby empowering teachers to face this new reality, in conjunction with a much needed digital inclusive education readiness.

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Pre-braille Implementation into Early Education: Tactile Activities to Introduce Braille Concepts to Kindergartners

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Contents

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Abstract

This study investigates the importance and affordances of implementing pre-braille activities in a kindergarten classroom, regardless of whether students have sight or have sight loss. We question what tools and/or support are needed to conduct greater, inclusive-based lessons in the classroom, and how awareness about the braille writing system could be introduced.

Semi-structured interviews and co-creation sessions were the methods used to gather information, in addition to the traditional literature review. Sessions were conducted with 13 participants. Through listening and learning from a community of experts, teachers, and parents, noted areas of support and needs were incorporated into the design process and discovery of design opportunities. The designed objects foster inclusive teachings, collaboration, and communication between students with all abilities.

Our analysis shows a strong correlation between pre-braille activities and kindergarten classroom teaching. Pre-braille activities work to build two-handed coordination, finger sensitivity, light touch, dexterity, and mobility, all important for reading braille, a tactile writing system.

We propose that integrating multiple modes of tactile engagement in the kindergarten classroom will increase interest in pre-braille and the braille writing system. This is especially important for those who later need to learn formal braille. The designed objects, a pouch fostering multiple modes of tactile engagement and an activity prompt system, act as inspiration pieces, allowing students and teachers to co-create activities in the classroom.

Keywords

Curriculum · Early education · Multisensory · Pedagogy · Pre-braille

Introduction

In early education, a period when development is at its highest and most significant, building foundational literacy skills is important for success, whether personal or academic (Dereli Iman et al., 2019). During the early grades in school, children will develop literacy skills by reading and writing. Students with sight loss develop these skills in the form of braille. Braille is a writing system for blind and partially sighted individuals (BPSI). It gained its first recognition in 1852 after Louis Braille's death (Tobin & Hill, 2015, p. 240). Obtaining a strong understanding of what braille is and how to use it can help an individual excel in school, work, and their personal life, overall, increasing confidence and independence. With technological advancements, students are using audiobooks and assistive technology to learn and complete assignments. Unfortunately, this does not assist the retention of braille writing and reading. Given the importance of braille writing skills for BPSI, and the connection of pre-braille to kindergarten classroom learning, this research aims to introduce braille concepts and emphasize pre-braille learning in kindergarten classrooms, regardless of whether students have sight loss or not.

My interest in the braille writing system stemmed from a project in my graduate studies focused on creating feasible braille signage in a university setting. Our team consisted of three researchers/designers, and two individuals who are blind. Working directly with the two BPSI, we were provided with the insights of support and needs people in the vision community require when navigating indoors. This fruitful experience, in combination with the creation of a children's story and activity book during my undergraduate studies, led to three topic areas: braille, pre-braille, and early education.

Pre-braille, or more recently referred to as early tactile strategies and exploration, works to develop fine motor skills and concept development. Motor skills, such as two-handed coordination, finger mobility, dexterity, and sensitivity, are explored naturally while discussing concepts such as physical weight, i.e., heavy and light. We see examples of pre-braille-like teachings in Montessori and Waldorf schools. The Casa program in Montessori education includes practical life and sensorial exercises to help train the hand (OMS Montessori, n.d.).

CASA, JK, and SK in Montessori (ages 2.5 years to 6 years) cost more than an undergraduate university degree for Canadian students in Ontario (Montessori The Place to Grow). Because Montessori and Waldorf education include sensory teachings but are not accessible to all (cost), I am researching the kindergarten classroom. Unlike Montessori or Waldorf education, the kindergarten classroom at public preschools is free to attend (paid for by taxes) (People for Education, 2021). Kindergarten holds an array of opportunities. It is a time when children first leave their home to learn, work, and play with kids of all abilities. The Ontario Kindergarten Program uses a play-based structure, incorporating processes of inquiry. Students will explore and question using an array of materials found in the classroom and outdoors (The Kindergarten Program, 2016, p. 23).

I am not teaching braille. Braille education requires qualifications of which I do not possess. My purpose is to work directly with kindergarten teachers and teachers of the visually impaired and respond to the following research questions:

By questioning sensory practices currently in place in the school environment,

- What tools and/or support might teachers need to conduct greater inclusive-based lessons in the classroom?
- How can we increase engagement in pre-braille and awareness about the braille writing system?

Through co-creation with teacher participants, we found design opportunities that led to the creation of an object (pouch) with multiple modes of tactile engagement and an activity prompt system. Both outputs can be used on their own or together by kindergarten students in collaboration with teachers in the classroom. The outputs foster inclusive teachings, engage early tactile strategies, and allow for collaboration and further communication between students with sight and students with sight loss.

Literature Review

Braille: A Tactile Writing System

In order to understand pre-braille, we must first discuss braille. Braille is a tactile writing system used for individuals who are blind or partially sighted (BPSI). Braille is made up of the cell, constructed of two columns and three rows, a total of six raised dots. Each number and letter share similarities as they are all created using the same cell format. Michael J Tobin, a professor of Special Education at the University of Birmingham, says braille is successful due to its consistent formation, even with slight alterations such as the addition of contractions and a sign to indicate a capital letter (2015, p. 240). There are two grades within the braille writing system, grade one and grade two. Grade one is typically used by those who are new to the writing system, and grade two is more advanced (Tennessee Council of the Blind, 2010). “Braille permits the exploration of a whole page of text, scanning of a sentence backwards and forwards, up and down the page” (Tobin & Hill, 2015, p. 246) (Fig. 1).

Developing braille literacy skills requires repetitive reading and writing practice, as well as linguistic and haptic skills (Oshima et al., 2014). The repetition further enhances muscle memory and information retention. Because braille requires different skills than reading visually, it is crucial for individuals with sight loss to learn braille as early as possible. This tactile writing system can be both read and written by people with sight (Tobin & Hill, 2015, p. 246). This allows opportunities for teachers, classmates, and parents to become familiar with braille to teach or assist those who are new to the writing system.

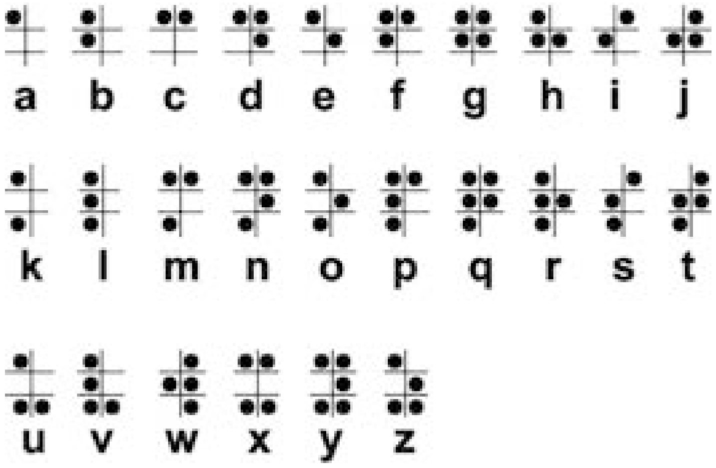


Fig. 1 The Braille alphabet (Idee, n.d.). Alt Text: Each letter in the English alphabet and its corresponding braille cell formation

Pre-braille: Strategies and Exploration of the Hands

Pre-braille, as it sounds, occurs before learning the formal braille writing system. Lynn Rollings and Darlene Urban, teachers at the W. Ross Macdonald School in Brantford Ontario, describe braille as read with the sense of touch (Rollings & Urban, n.d.). Therefore, one must first develop finger sensitivity, mobility, dexterity, two-handed coordination, and other strategies helpful to becoming attuned to tactile perception. Well-known in the deafblind community, Lilli Nielsen, a former preschool teacher, psychologist, and teacher of the blind, outlines examples of pre-braille activities: sorting and stacking, distinguishing between a variety of textures, completing tracking worksheets, stringing buttons or beads, crumpling pieces of paper, manipulating clay, and winding up toys or timers (Nielsen, 1994).

Both “Paths To Literacy,” a resource site for students with sight loss, and an interview with a manager of a Blind-Low Vision Interventionist Program discussed the importance of concept development in pre-braille (Gwyn52, 2015). Working on tactual awareness and fine motor skills are more easily understood through concept teaching. Without sight, concepts must be taught deliberately (Knight, 2014). Example activities to teach concept development are as follows: creating a nature basket, a story box, and stacking or nesting. A story box includes a number of objects in a bag or box that are used during the appropriate time when telling a story (Drissel, n.d.). This creates a more exciting and interactive story time experience (Knight, 2014).

Storytelling is also a valuable method for learning, especially when learning literacy skills. Storybooks allow for periods of creativity and imagination, collaborative reading between the teacher and student, and encourage exploration (Beginning Literacy Development at Home). Stories can help articulate concepts and are therefore a reason we see the creation of the story box. Unfortunately, this powerful learning tool is not always available to families of BPSI, and braille books are much larger and longer than those without braille. Given the importance of concept building and storytelling, I brought the explorative and sensory features of story boxes to the proposed design outcomes (Fig. 2).

Montessori Education: Tactile Activities in Use

Montessori and Waldorf-style education models emphasize hands-on learning and collaborative play. Maria Montessori, an Italian physician in the early 1900s, worked to create a new approach to education, one that would allow children to reach their full potential. The Casa program in Montessori, referring to the age bracket of 2.5 to 6 years old, develops practical life skills, contains sensorial and cultural activities, and incorporates movement and art into every subject (Lillard, 2018).

The following are examples of practical, sensorial, and cultural activities, as outlined in a Montessori school, located in Chatham Ontario (Montessori The Place to Grow, n.d.).

Fig. 2 Story box example (Image by the Author 2021). Alt Text: Picnic objects to be used when telling a story related to a picnic. A basket on its side. A blanket with a plate on top. A fork, spoon, and cup sit on the plate

- Practical: Pouring liquids, polishing, sweeping, dusting, and washing tables, all introduce independence and self-confidence to students.
- Sensorial: Taking things apart and putting them back together helps develop curiosity and discovery.
- Cultural: Exercises in geography, history, and sciences help students understand the world they inhabit.

The artistic expression and display in Montessori and Waldorf schools are typically visually focused. Children without sight are not able to learn incidentally like their classmates with sight. Incidental learning, or learning through observation and repetition, is a large part of how we learn, especially at a young age. Langley, a teacher of students with profound visual and multiple handicaps, states, “Visually impaired children rarely used objects that deviated from day-to-day experiences” (1985, p. 103). The first time a child with sight loss is presented an object, it is the first time they are experiencing it. This was especially helpful to remember during the design process as the outcome benefits both students with sight and with sight loss. The objects used in the designed outcome have a sense of familiarity to students with sight loss.

Ontario’s Kindergarten Classroom: Play-Based and Student-Led Learning

The kindergarten classroom takes a play-based learning approach. It is found that this type of education has “lasting benefits for children’s reading, writing, numeracy, self-regulation and social skills" (Building Better Schools, 2019). Several centers in the classroom allow for small groups, large groups, and one-on-one learning time. The classroom centers include materials for all types of collaboration, such as whiteboards and markers, sand, and playdough. The Ontario Kindergarten model benefits from two types of educators in one classroom at a time. One, a certified teacher has knowledge of the elementary curriculum outlined by the Ministry of Education, and two, a designated early childhood educator (DECE) brings knowledge of learning needs for children ages birth to 5 years old (Building Better Schools, 2019). Two educators allow for more time getting to know each student and their unique way of learning.

The Ontario Kindergarten Program 2016 describes the child and teacher as co-learners. A child will engage in inquiry when supported by the teacher. Example acts of inquiry are: "exploring objects and events, making observations using all five senses and generating questions, gathering, comparing, sorting, and notice patterns" (The Kindergarten Program, 2016, p. 23). This is supported through the educator posing open-ended questions, providing a variety of materials, modeling how to plan, and asking questions which expand upon the child's thinking. Already, I have noted a strong correlation between kindergarten's acts of inquiry (exploring objects using all five senses) and pre-braille activities (sorting, stacking, manipulating clay, etc.). The connection between pre-braille and kindergarten learning was only made possible through literature review and discussions with kindergarten teachers. Literacy learning in kindergarten is, in fact, very similar to pre-braille. Many teachers noted in interviews that pre-braille could be referred to as pre-reading for children with sight.

Young students are growing up in a very digital time and therefore develop digital literacy at a young age. With the rise of technology, BPSI are beginning to read acoustically, i.e., listening to audio textbooks instead of writing and/or reading braille. Some students in higher education say there is limited time to complete homework, so reading acoustically has become a staple practice, says Vassilios Argyropoulous, a member of the Department of Special Education at the University of Thessaly, and Aineias Martos, who works at the Center of Education and Rehabilitation for the Blind (2006, p. 3). This poses an issue because without frequent literacy practice such as reading and writing braille, braille retention may be lost. This is especially unfortunate, because it is known that developing braille literacy skills can assist with employment, schooling, independence, and overall happiness (Argypopoul & Martos, 2006). It is therefore crucial that we integrate pre-braille activities into early education, hoping students without sight, or those who lose sight later, will be more apt to continue reading braille moving into higher education.

Toys as Learning Tools

A team in India, including individuals with design and vision rehabilitation knowledge, describes the impact of play-based learning as "promoting social skills, emotional development, sensory awareness, and communication, along with helping children develop fine and gross motor skills" (Jain et al., 2018, p. 902). There are many types of toys promoting learning and play simultaneously; examples can be seen in Montessori classrooms. There are wooden and plastic toys made to practice stacking and sorting, matching like-shapes, counting, and connecting. These types of toys are durable and effective teaching methods.

Concepts in mathematics can be more clearly described through 3D objects, which help visualize concepts related to counting and space. The second semester of kindergarten introduces 3D shapes to explore relationships and properties (Kinzer et al., 2016). Fittle, a 3D-printed puzzle created in India, recognizes that blocks are accessible thinking tools and effective modes for reasoning, modeling, and constructing. The Fittle puzzles contain several blocks, each embossed with English Braille. Once adjoined, the pieces create an object with the object name included on top. A child with sight loss is then able to read, for example, fish in English Braille, while feeling the shape of a fish.

Review and Next Steps

The following bullet points started out as a quick reminder to myself when reflecting on what the literature review taught me and how it informs the design. I have left the bullet points allowing for a cursory overview and reflection period.

- Braille is a tactile writing system, typically used for those who are blind or partially sighted (BPSI). This writing system helps empower individuals, as they are often more successful in work and school with knowledge of braille.
- Pre-braille, more recently referred to as early tactile strategies and exploration, is typically learned before formal braille, grade one and two. It allows individuals to build strength in their fingers and hands (the tools they will be reading and writing with).
- Both Montessori or Waldorf education (private sector) and Ontario's kindergartens (public sector) implement tactile activities in their teachings, Montessori and Waldorf maybe more so. But these alternative education models are not accessible (cost wise) to all.
- From observation and research of toys present in kindergarten classrooms, I have noted they are often one-dimension, meaning, one toy will allow for stacking, but not other activities like stringing, crumpling, zipping, and further manipulating.
- Play-based learning and toys promote social skills, emotional development, communication, etc., important for future learning and growth.

Methodology and Methods

I conducted qualitative and participatory research methodologies. Qualitative research involves collecting and analyzing nonnumerical data to gather in-depth insights (Bhandari, 2020). Participatory research emphasizes the perspectives and priorities of participants. It can be defined as "systematic inquiry in direct collaboration with those affected by the issue being studied" (Vaughn & Jacquez, 2020). Both methodologies were chosen as they align well with inclusive design practices. Inclusive design assesses and evaluates the needs and barriers of participants often not acknowledged in current systems. The methods used included semi-structured interviews, co-design, and feedback sessions with teacher participants.

Participants and Recruitment

Because I would be working directly with individuals, research ethics (REB) needed to be completed. I gained REB approval (#101812) on June 26, 2020. This meant I was able to prepare for interviews early. Just 3 months before REB approval, our world entered a global COVID-19 pandemic resulting in lockdowns and isolation practices. Participant recruiting was deemed more difficult than initially expected. Teachers were finding creative solutions to conduct their lessons digitally, and parents, in many cases, became their child's primary teacher. As to not burden early educators with further stress, I looked to retired kindergarten teachers and those on maternity leave. These participants held immense knowledge and practice teaching. As of October 2020, some teachers who were teaching kindergarten during the COVID-19 pandemic and learning how to adjust to teaching online indicated their availability to participate in research. I was then able to interview not only retired kindergarten teachers but also current practicing teachers. Conversations with teachers of the visually impaired (TVIs) and mobility and orientation (O&M) specialists occurred later in the research process, March and April 2021.

In the following sections, I will describe the chosen methods and what was learned from each.

Semi-structured Interviews and Understanding Data

A semi-structured interview allows for more discussion-based conversation than a fully structured interview. In general, semi-structured interviews are commonly practiced in qualitative research, allowing the researcher to listen and reflect on participant's real-life scenarios, stories, and expertise, a depth of knowledge not gained by a literature review alone. Interviewees expanded on what I had studied and revealed new points of view, which further enriched my research and, ultimately, the designed outcomes. I was able to interview a pre-braille specialist, two Principles of Montessori-based schools, a parent of a child with sight loss, six kindergarten teachers, and three teachers of the visually impaired (TVI), each bringing detailed knowledge of early education, ranging from daily structure, activity types, and communication between the teacher, student, and parent. The participants interviewed are in the Greater Toronto Area (GTA) and Niagara Region in Ontario, Canada. With permission granted, interviews were recorded for the purpose of transcription and deleted once notes were complete. The list of questions was provided one day prior to the interview phone call.

I was used to coding as a natural next step following interviews, but in processing this information, I discovered that trying to codify majority needs and findings meant I was excluding individuals that did not "fit" the majority. This realization came only after conducting initial coding into categories, i.e., government and curriculum, age group and type of teaching, teacher-parent-student relationships, etc. Instead of showing you the coded findings, I present some similarities found, but also the needs and barriers of participants.

Some areas of recurring practices and needs mentioned are as follows:

Practices

- Incorporating sensory activities.
  - Activities are sometimes conducted outside to engage the senses in ways the classroom cannot.
  - Tactile engagement is integrated in the kindergarten curriculum and must continue to be integrated and developed upon.
- Technology integration is different from school to school but implemented in all to a certain degree.

Needs

- Support: for teachers, parents, and students with disabilities
  - Greater teacher support within the classroom
  - Stronger communication between parents and teachers
- A need for more open discussions related to sight loss and other abilities

I have broken down the following findings into areas within kindergarten education that displayed barriers, needs, and successes, reflecting of the bullet points above.

The Value of Incorporating Sensory Activities

This section assesses the types of tactile engagement integrated in the kindergarten curriculum as well as the types of activities conducted outside. It was confirmed during conversations with participants that pre-braille activities, such as hand and finger strength, mobility, and dexterity, are examples of literacy learning. By practicing tactile activities such as collecting materials outside that have the same size or texture, students are learning important skills for reading and writing.

When we discussed types of sensory and tactile activities, the mention of outdoors appeared repeatedly. "Forest schools" was a new term to me. This idea has been incorporated into many schools. It is an allotted time per week that students are taken outside to learn. If there is a forest or park nearby, the "forest school" will take place there. Learning outdoors offers opportunities to touch, smell, and hear differently than indoors. Science is also a subject that allows for more sensory learning and learning that can be done outside. For example, exploring the concept of growth, freezing, or thawing by observing a plant grow and seasons change.

In an interview with teacher participant G, a teacher of the visually impaired (TVI), they discussed that in the event of a class trip outdoors, to say a nature conservatory, a pre-made kit will be delivered (during the COVID-19 pandemic) to the student with sight loss. The parents will then assist the child while the TVI explores the kit with the student virtually. This kit might include a branch asking to be smelt, handled and manipulated, and seeds, able to be cracked in the students' teeth. Exploring the kit in advance allows the child the attention, knowledge, and sensory experiences before attending the trip with their peers.

Everything using fine motor, i.e., manipulating smaller objects, connects to pre-braille learning. Understanding the importance of these tactile experiences and its connection to literacy and braille learning affected the tactile pouch outcome co-designed by myself and teacher participants. Reflecting on the benefits of the pre-made kit in the example above, the co-designed pouch uses a variety of textures including rough Velcro, soft denim, hard plastic zippers, and smooth laces. Exposure to different textures will improve sense of touch and ultimately reading.

Technology

This section looks at the type and degree in which technology is used in the classroom. I am defining technology as assistive tools requiring internet connection, i.e., iPads or computers to use websites and applications. Because students are growing up in an increasingly digital age, technology is becoming less foreign to children. All teacher participants mentioned some amount and type of technology used in the classroom, each at slightly different levels. In this case, some classrooms introduced math manipulatives, hands-on tools to solve math problems. Other classrooms are using sites like gfletchy.com, where math problems are presented in the form of short commercials. These example tools and/or technology offer auditory and tactile strategies, differing from the previously taught math problems conducted on worksheets. These have proved to be more effective, fun, and not limiting to sight dependency. It is important to note that the type of technology available in the classroom is dependent on financial conditions and funding available.

For BPSI, technology can be impactful and lead to increased independence and confidence. Some of the technology present in an elementary classroom for BPSI are a Mountbatten Brailler and a Victor Stratus Reader (audiobook player). Other technologies introduced are audio devices, electronic books, and screen readers, all of which are described as assistive technologies.

Support: For Teachers, Parents, and Students with Disabilities

This section is reflective of the need for greater teacher support within the classroom as well as a need for stronger communication between parents and teachers. While teachers do their best, there is never enough time to support all students, especially in classes with 20+ children (typical in Toronto public schools). Teacher participant B said, "teachers need the same support a child needs." This being the case, they feel as though parental support, to reinforce learning being done in the classroom at home, would be helpful, as well as extra and specialized support professionals in the classroom. Strategies to support students with sight loss and/or other learning disabilities from the point of view of kindergarten teachers looked like: chunking work into manageable pieces, enlarging content, using assistive technology (dictation applications), creating unique tasks and visual schedules, having the student sit closer to the teacher, and helping kids understand what they are feeling. TVIs noted the importance of students with sight loss to be at the same pace as their classmates. A suggestion was support over the summer months, a time when pre-braille practice can be lost and/or delayed.

Support over the summer for BPSI shows promise for future opportunity and development of this research project.

Parents are the first teachers of their children, and they have a lot to share with classroom teachers if given the opportunity. This research focused on teacher insights. Further research would benefit from conversations with parents. Reading exercises and at-home literacy practices were briefly discussed with teacher participants who are also parents of young children. Primary discussions about parents were in conversation with teachers and how teachers interact and bring parents into the child's learning. Some teacher participants suggested ways for parents to continue classroom learning in the home. One of these suggestions was going on a walk with your child and asking simple and effective questions, enforcing curiosity and inquiry.

Unexpected Findings

While there were some similarities shared across teacher participants related to types of activities taught on a day-to-day basis, there were also unexpected findings. Firstly, the importance of technology was particularly crucial to the one parent participant interviewed. Again, this would be interesting to explore with more parent participants in future studies. This parent has a child with sight loss and noted a lack of support for their child in the school setting, particularly in older elementary grades. They also made clear they wished their child would have more practice and exposure to technology in the classroom. "I want my child to be able to participate in the 21st Century." Although important to note, the initial design in this research does not include technology, as producing something feasible to many was a priority; something that can be constructed by teachers and guardians if they are unable to purchase tools. Activity prompts are able to be shared physically or digitally and printed at a low-to-no cost.

Teacher participant C discussed the use of technology in their classroom. Since the beginning of the COVID-19 pandemic, this participant has looked to platforms like Twitter to help engage parents with the student's classroom work and learnings. Other classroom teachers are making use of Google Classroom and conversations with parents and/or guardians via Zoom. The types of technology and platforms used were dependent on the teacher and parent interest. A TVI noted that their student caseload is approximately 70 students. This is not typical. It had increased when learning no longer took place in-person. Here, an opportunity emerged to develop a community platform or forum for teachers of the visually impaired to share experiences and expertise. Teacher J said “This job can be lonely. There aren’t many of us.” As a result, internal motivation is crucial to succeed in a job of a TVI.

With unexpected findings, I was able to incorporate unique barriers and needs that arose in the designed outcomes. The created activity prompt system (as seen in the section “Working Practices”) may be a starting point for a community sharing project. Because the prompts are modular, they offer customization. It is my hope that teachers will add to and refine the activity prompts to then be shared within the community. This is a first step to addressing the need for a community where TVIs can share experiences, concerns, and material. Other unique needs that arose in this section “Unexpected Findings” have created a space for new inclusive projects.

Co-design

I have learned to adapt both the language and design used throughout this project process. When introducing the idea of co-design sessions to participants, there was hesitation. Many people hear the word design and if they do not have a design background, they feel fearful. Adjusting the name to co-creation or workshop allowed for a greater ease and welcoming nature to the process. Going forward, I will be toggling back and forth between the terms co-design and co-creation.

As I learned in the Inclusive Design Master program, co-design means recognizing that your participants are the experts – experts in a field of study and in real-life experiences. I considered how co-design could be used as part of this project. By co-designing, we can learn from participant’s unique experiences and begin to design systems, products, etc., that address the needs and barriers of people who are not considered the majority. I co-designed with kindergarten teachers and teachers of the visually impaired. Whether currently teaching, retired, or specialized, i.e., an orientation and mobility specialist (O&M), all teachers have rich experience and unique styles of teaching to learn from. Co-design is an important part of inclusive design. It is one of the three dimensions outlined by Jutta Treviranus, director of the Inclusive Design Research Centre at OCAD University. “Use inclusive, open and transparent processes, and co-design with people who have a diversity of perspectives, including people that can’t use or have difficulty using the current designs” (Inclusive Design Research Centre, n.d.). The purpose of the co-design sessions was to have teacher participants design a multisensory kit including objects and activities that could be used in the classroom, whether the students have sight loss or not. It is important to reinforce that during a co-design session, I, as a facilitator, am meant to actively listen and guide when needed. The designed outcome is to be created by the participants without influence or bias.

Co-design sessions are an appropriate and effective method when conducting participatory research. They allow for learning and feedback from individuals constantly working with the intended age group. We arrived at co-designing a multisensory kit from literature and interview findings. Co-designing the proposed design outcomes allowed for most needs to be met. The importance of play for learning and retention of information, tactile activities in place in the kindergarten classroom, and an opportunity for more inclusive conversations, naturally developed to a kit (object and activities). A need arose for objects with multiple modes of tactile engagement, one that allows for manipulation of large objects and small, each requiring different finger and hand manipulations. I am naming the designed object a tactile pouch as it offers multiple modes of tactile and pre-braille practice, i.e., collecting and sorting as well as more fine motor development (wrapping a string around a button). Design decisions for the tactile pouch are discussed in greater detail in ▶ Chap. 34, "Monstrous Intersectionalities." Beneficial to the design was knowledge of materials that are safe for the kindergarten classroom, what a child would be most engaged with whether having sight loss or not, and how classroom activities could integrate the tactile object.

Co-design Session Reflection

A number of co-design sessions were set up in order to learn from participant's creations. The created outcomes highlighted types of materials, what participants would like incorporated into the classroom and what they could do without. The first session did not go as planned, which had its benefits: unique learning opportunities! It compelled me to reflect on different setups for future sessions. The first co-design in practice was more conversational. I posed a few questions at the start, i.e., Is the kit used outside or inside? Does it only contain activities specific to one subject area? Conversations deviated from the posed questions and included the sharing of techniques and current experiences in the classroom. I predict both participants were curious about one another's background and not enough time was allotted for them to get to know each other outside the conducted co-design. The opportunity to converse during breaks, for example, would have been more natural in an in-person setting. Due to the COVID-19 pandemic, the co-design session took place via a three-way phone call. This posed its own challenges, as we had no indicator of who was to speak next. Understanding it can be uncomfortable speaking to multiple strangers on the phone or in a video chat, I decided asynchronous activities would be more valuable for both participants and myself.

Asynchronous Activity Co-creation

As a result of busy schedules and excessive time spent in front of screens, an asynchronous activity (not in real time) was proposed. The asynchronous activity allowed participants the time to test without the stresses of scheduling and planning with other participants. Each participant was given an introduction to the research project, a warm-up activity to help them feel more relaxed with the idea of designing, and a formal activity. After about a week, a follow-up call was scheduled to discuss thoughts and findings.

1. The formal activity is as follows: Inspired by action words used in pre-braille, i.e., sorting, stacking, stringing, twisting, matching, grouping, comparing, and tracking. Make something that incorporates the act of stacking; or
2. Stack your collected materials (a suggested list was provided beforehand)

The activity then asked participants to consider the materials they used. Posing questions like: Is the material safe for a kindergarten classroom? Is it a found material? Can you see this material transferring to other pre-braille activities?

Review and Response to the Asynchronous Activity

Although it appears the asynchronous activity was only conducted by two individuals (looking at the figure above), multiple teachers participated. I believe some felt more comfortable speaking to their design without photos of what they had created. In the future, it may be beneficial to ask participants to record not the outcome but the materials used. This on its own is extremely beneficial to the design process. As seen in Table 1, many of the materials used can be found in the home and a kindergarten classroom. Conversations were had about sizing of beads, the kitchen-friendly ingredients of playdough, and repurposing materials post-use. Most interesting to note is that kindergarten includes a large age range of approximately 3–6 year olds. Older students in kindergarten may have no trouble using their pincer grasp when

Table 1 Asynchronous activity findings

Creations by participants	Materials	Observations
	Marker lids Sort by color and size As marker wears out, collect lids Buttons A staple in the classroom Playdough Moldable, holds its shape and takes on various forms Often used recycled materials in classroom when discussing shapes	The smaller the material, the more agile and precise one has to be Playdough allows for different hand strength and muscles to be used Material like wood does not allow for same sort of manipulation
	Playdough Can be made at home or in the classroom Stamp letters in playdough Beads Reusable Different colors used for matching and sorting activities Pipe cleaners Reusable Used to form letters All materials safe for kindergarten classroom	Conducting activity required: Hand-eye coordination Depth perception Pincer grasp to pick up individual objects, i.e., bead Activity would have been easier with larger materials Beads with larger hole Cut-up rings of paper towel roll

Alt Text: Three columns and two rows. From left to right: creations by participants, materials, and observations. There are two creations, the first uses playdough, marker lids, and buttons. The second uses playdough, pipe cleaners, and beads manipulating beads; younger students, on the other hand, may need larger objects to start with. This made it clear that the materials used with the tactile pouch should be inspired from assessing where the child is at in terms of their fine motor skills, hand-eye coordination, and depth perception. A solution may be to have beads (and other materials) of different sizes in the classroom so students can choose and use what they feel comfortable with and/or are able to manipulate. It is also important to use found and recycled materials, as mentioned by multiple participants. As to be inclusive to both students with sight loss and students with sight, materials might be limited to those BPSI are familiar with, although materials will likely be customized by the classroom teacher and students.

Feedback Sessions

I showed teacher participants early sketches following the asynchronous activity for further design feedback. When looking at early sketches of the tactile pouch, teacher participant G suggested the pouch fit on the child's lap, as kindergartners like to work on the floor where there is more room and less confined space. In terms of activity prompts for teachers, participant G thought there might be a way to allow teachers to create activities based on observing how their students interact with it. "Place the pouch on the math table and see how kids interact. Are they stacking? Sorting? Stringing?" depending on their range of skill and manipulation ability, especially with smaller objects.

Another conversation led to insights about a kindergartner's work ethic. "Kids are able to build at this age. They are also result and goal-driven." This highlights the importance of keeping activities challenging. This could be addressed through levels or layers within the pouch, or modifications to activities, i.e., a prompt that is relatively easy (to manipulate) and one that requires more fine motor challenges. The tactile pouch could include Velcro and buttons in the first layer, and string in the second. The levels and/or layers would allow the child to work through different tasks and manipulate their fingers in different ways in isolation.

Working Practices

This section takes knowledge learned from research, interviews, and co-creation with kindergarten teachers and teachers of the visually impaired (TVI), to describe how the design came to be. Sections within the chapter explore materials and prototypes for both the pouch and activity prompt system.

Co-creating with teacher participants meant designing and reviewing the tactile pouch and activity system's benefits, safety, and mutability. It is my goal that with the design outcomes in hand, teachers and kindergartners will work together to explore textures in a safe space, while simultaneously conversing about what it means to read tactually.

Inspiring the Design

As stated in Ontario’s Kindergarten Program 2016 (first mentioned in the section “Literature Review”), children are engaged in inquiry when they “gather, compare, sort, classify, order, interpret, describe observable characteristics and properties, notice patterns, and draw conclusions, using a variety of simple tools and materials” (The Kindergarten Program, 2016, p. 23). These acts connect well with pre-braille activities, i.e., sorting, left and right, tracking, matching, stringing, and lacing (Rollings & Urban, n.d.). The activity prompt system was inspired by a need for ideas and/or suggestions on how one might use the pouch for classroom activities. When constructing activities with teacher participants, we noted distinctions between learning outcomes, settings (outdoor versus indoor), and the pre-braille actions themselves. The prompts then evolved to become a modular system, allowing mixing and matching between options related to the three distinctions. More detail about the modularity can be read in the section “Activity Prompt System.”

Material Exploration

As my research focuses on the sense of touch, it became increasingly crucial to test materials that could be used in the kindergarten classroom, as well as receive feedback from teachers to confirm whether the materials were appropriate. Materials with unique textures allow us to develop finger sensitivity, but also an understanding of usability and safety. Therefore, materials chosen based on appropriateness, effectiveness, and multiple purposes, i.e., safe for the students and classroom, resulting in thoughtful teachings, and able to be used by both BPSI and students with sight.

A resource from the Inclusive Design Research Centre’s SNOW project, titled “One is Fun, Guidelines for Better Braille Literacy” by Marjorie Troughton, reinforced the materials and actions that should be used when beginning to learn braille as a child. “Interesting books for preschool readers include cloth, zippers, buttons, magnets, Velcro, action figures, pockets, etc. as well as books of different shapes” (Troughton, 1992, p. 33) (Table 2).

Table 2 represents the review and testing of materials found in my apartment, outlining the advantages, disadvantages, and relationships to pre-braille activities. Materials were chosen based on what I already had and/or what I could access during the COVID-19 pandemic. The benefit to using found and familiar materials during testing was that many of these materials would also be accessible to teachers and parents. A creatively inclined parent might use these materials to make their own tactile pouch. The items tested were inspired by a pre-braille document shared with me by a manager in the Blind Low-Vision Early Intervention Program at Surrey Place, as well as being mindful about what children use and how they play. As you can see in the above figure, wood is a sturdy material with structural

Table 2 Sample material exploration chart

Photograph	Material	Advantages	Disadvantages	Activity (Pre-braille)
	Wood	Sturdy Structural integrity	Can be heavy Difficult to transport Requires additional tools for manipulation Splinters	Blocks used for stacking and sorting Noticing patterns
	Rope	Available Used to teach tying shoes	Dangerous if too long Requires advanced fine motor development	Stringing (fine motor) Two-handed coordination Pincer and grasp
	Fabric	Variety of textures Beneficial to develop finger sensitivity	Some available Subconsciously teaches material waste	Differentiating textures (rough and smooth) Matching Comparing
	Magnet	Variety of objects used with magnets Move and manipulate attached objects Portable	Magnets work with water?	Sort Group Track and trace fingers over objects

Alt Text: Five columns and four rows. The columns from left to right read: photograph, material, advantages, disadvantages, and activity (pre-braille). The four materials photographed are: wood, rope, fabric, and magnet

integrity but can be heavy, difficult to transport, and may need additional tools for manipulation. Magnets include a variety of benefits for exploration. They can be moved to different locations, allow for manipulation of objects, and are small enough for transport.

Design Ideation

Before beginning to prototype objects and activities, I revisited my research questions in more detail. This allowed me to clearly outline the specific needs that arose from discussions with participants, needs that would be addressed in the final design outcomes.

Research Questions Revisited

What tools and/or support might teachers need to conduct greater inclusive-based lessons in the classroom?

As gathered from interviews, teachers are looking for further support, whether that is in the classroom or at home. There is an opportunity to continue learning in the home environment, but it requires strong communication of expectations between parents and teachers. Teachers are interested in more manipulatives and tools to use in their teaching; however, these tools can often be expensive. As a result, students share and work with them in small groups. Here, an opportunity for an educational tool at a low-to-no-cost emerged.

How can we increase engagement in pre-braille and awareness about the braille writing system?

Ways of engaging in new material might include: play-based inquiry, the outdoors, manipulatives, and engagement in multisensory activities, all tactics used in kindergarten teaching. These types of learning are found to be most important at this stage of development. I use the example of egg cartons simulating the braille cell in the activity prompt systems, seen in the section "Designed Outcomes." This idea was inspired by a teacher participant who had experience and success using this specific material when discussing braille. Objects like egg cartons, cut in half, offer an introduction to the braille cell formation. Both the halved egg carton and braille cell consist of two columns and three rows. When stones or marbles (objects found outside and inside the classroom) are placed in the carton divots, the braille writing system is simulated. There are many activities that can spark discussion about the braille writing system. The activity prompt system will help with initial pre-braille activity ideas and construction.

Tactile Pouch

Early design ideas for the tactile object used a wooden board as a starting point. The board was to have carved out circle depressions which would then be filled with materials like marbles, allowing children to track and trace their hand over the objects (see Fig. 3). In discussion with participants, it became apparent that a wooden board may not be the best material for kindergartners. Although sturdy and long-lasting, wood is heavy, especially if the students are meant to carry this board to and from school. Wood also poses challenges when it comes to cleaning and disinfecting (something that should be considered during the global COVID-19 pandemic).

A magnetic sheet became a unique solution to a wooden board base. The magnetic sheet rolled up easily, making transportation simple. Magnets allow for the exploration of materials on a variety of planes, i.e., upside down and on an angle.

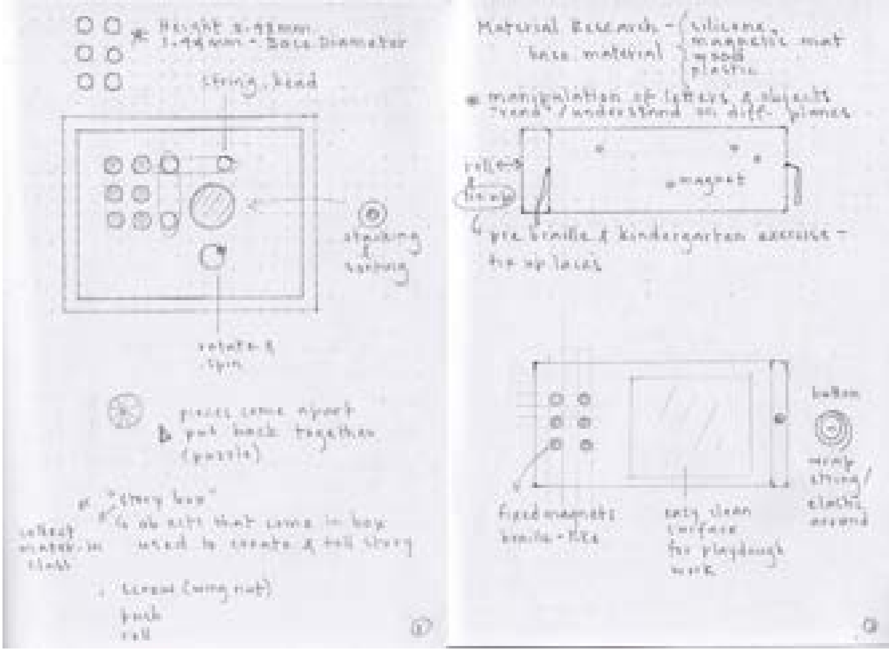


Fig. 3 Object design sketches (Drawings by the Author 2021). Alt Text *Design Sketch A*: A pencil drawing of a wooden board with circle depressions. Alt Text *Design Sketch* B: A pencil drawing of a magnetic sheet rolled out flat. Small circle magnets rest on top. String is drawn at the end of the sheet to show it rolls up and ties closed

For the magnetic sheet to hold or contain opportunities for other activities, it was decided to wrap it in fabric. The fabric would allow for sewn-on pockets, zippers, Velcro, and buttons, each requiring unique hand position, movement, and other considerations (Fig. 4).

The figures above show a prototype for a tactile pouch. Using paper and fabric to prototype made for quick and multiple iterations. Three contrasting colors were chosen, a light gray, red, and black, with the knowledge that people with partial sight can see some color. The pouch itself will be 16 in by 12 in. This size will fit within a child's lap so that they can use it in any location and/or position. The front, in a washable fabric, will contain: two pockets and additional magnets. Each attachment, i.e., pocket, has its own unique purpose and function. The pockets are meant for collecting, sorting, and matching pre-braille activities. The magnets supplied with the pouch can be used in conjunction with objects throughout the classroom. The magnet can attach to the object (with a sticker backing) allowing for manipulation and comprehension on different planes. The backside of the pouch will primarily be used with a Velcro patch and Velcro stickers. Attached is one pocket at 6.25 in, able to hold collected materials such as fabric scraps. The fabric scraps, when attached to

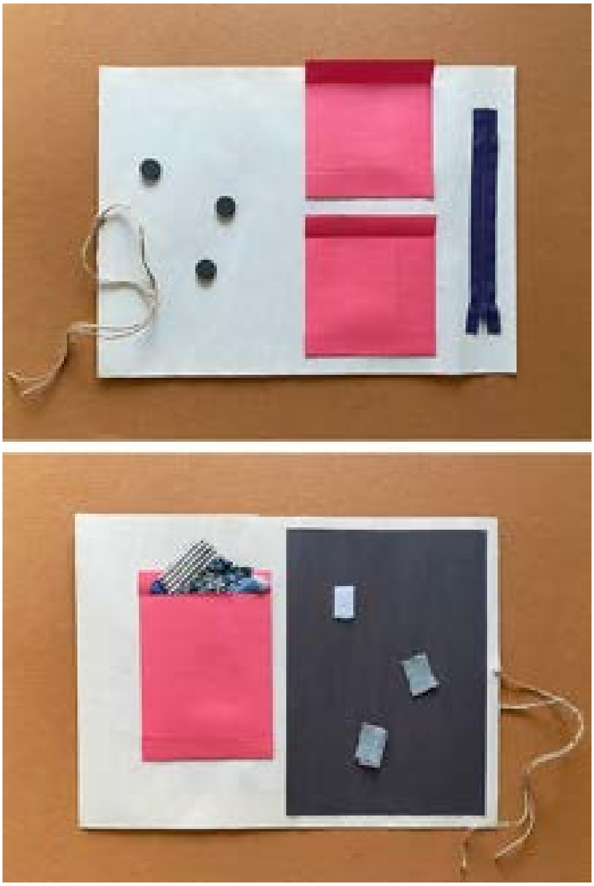


Fig. 4 Paper prototype. (Prototypes by the Author 2021). Alt Text *Prototype* A: A paper prototype to size, 12 by 16 inches. A light gray paper rectangle represents a fabric pouch. On one side of the rectangle are two red pockets. To the left are three small magnets and a string. To the right of the pockets is a zipper. Alt Text *Prototype* B: The same light gray paper rectangle flipped over to show the backside. Left of the center is one red paper pocket with fabric coming out. Right of the center is a large black paper rectangle representing a Velcro patch. Pieces of fabric are stuck to the Velcro patch

the pouch with Velcro, permit tracing and tracking, noticing different and like-textures (Table 3).

Activity Prompt System

The activity prompt system includes suggestions and prompts related to materials, settings, context, pre-braille activities, etc., helping kindergarten teachers create classroom activities that foster pre-braille practice and introduce the braille writing system. The system includes ten settings, ten pre-braille actions, and ten learning outcomes. These 30 prompts can be mixed and matched to create 1000 unique activities. In addition to the prompts, the system, titled “Introduction to Sensory Learning,” includes eight grouping suggestions for initial activity ideation, two

Table 3 Pocket and clasp exploration

Section	Type	Image	Pros	Cons
Pocket	Button		A pre-braille activity Requires more fine motor movement	Needs a large flap to prevent materials from falling out
	Velcro		Easy to use Effective for younger kindergarten students	Could wear over time; lose traction
	Clasp		Uses many pre-braille activities, i.e., finger strength, fine motor movement, and two-handed coordination	Could be difficult to manipulate for younger ages Requires fine motor and finger strength

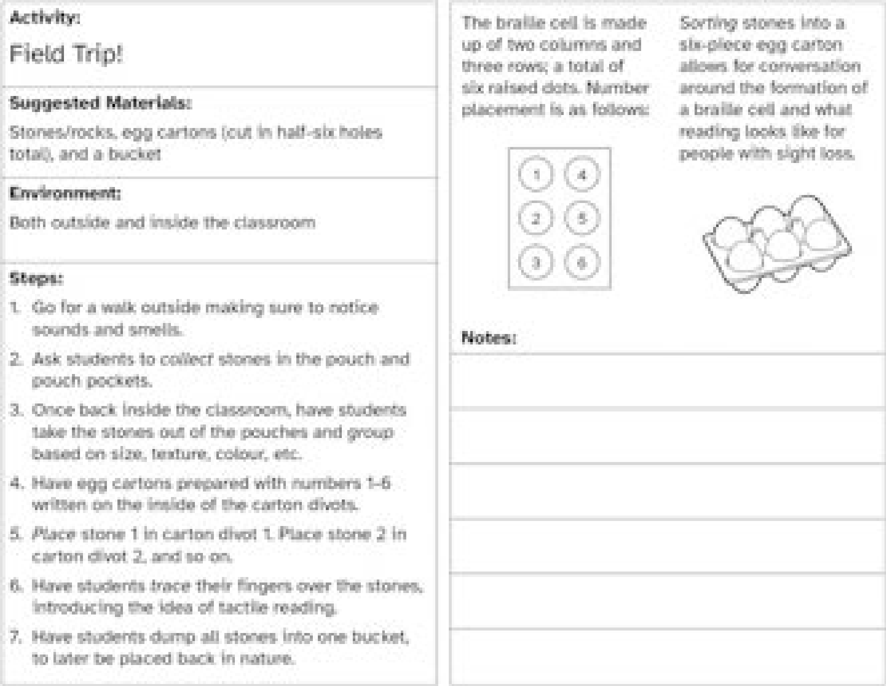
Alt Text: A table exploring three types of pockets, all made of paper. Pocket fastenings from top to bottom are: button, Velcro, and clasp. To the right of each pocket prototype are pros and cons of each fastening

detailed examples, and blank activity cards for personalized groupings and recording of activity creations.

The activity prompt system became modular after an initial version was completed (see Fig. 5).

The proposed activity "Field Trip," could be done either inside, outside, or both, splitting the time between the two. There was also a chance to use stones, marbles, etc., depending on the activity setting. An opportunity for mixing and matching materials and locations (environment) became clear.

The next version, as seen in Fig. 6, introduced a modular system. Modularity allowed the system to be accessible to any teacher, no matter what materials and objects they have in their classroom. They can use the system in consultation with the Ontario Kindergarten Program 2016, specifically, the learning outcomes in the document, as well as the space and materials available to them. While speaking with teacher participants early in the design process, it became clear that the messaging was not detailed enough. It was only after explaining via phone calls that they understood completely what the cards were meant to do. To clarify the modularity, three shapes were used to distinguish the prompts setting, pre-braille action, and learning outcome. The shapes as well as the colors dedicated to each shape improved the clarity and recognition of the system.



Activity:

Field Trip!

Suggested Materials:

Stones/rocks, egg cartons (cut in half-six holes total), and a bucket

Environment:

Both outside and inside the classroom

Steps:

1. Go for a walk outside making sure to notice sounds and smells.
2. Ask students to collect stones in the pouch and pouch pockets.
3. Once back inside the classroom, have students take the stones out of the pouches and group based on size, texture, colour, etc.
4. Have egg cartons prepared with numbers 1-6 written on the inside of the carton divots.
5. Place stone 1 in carton divot 1. Place stone 2 in carton divot 2, and so on.
6. Have students trace their fingers over the stones, introducing the idea of tactile reading.
7. Have students dump all stones into one bucket, to later be placed back in nature.

The braille cell is made up of two columns and three rows; a total of six raised dots. Number placement is as follows:

Sorting stones into a six-piece egg carton allows for conversation around the formation of a braille cell and what reading looks like for people with sight loss.

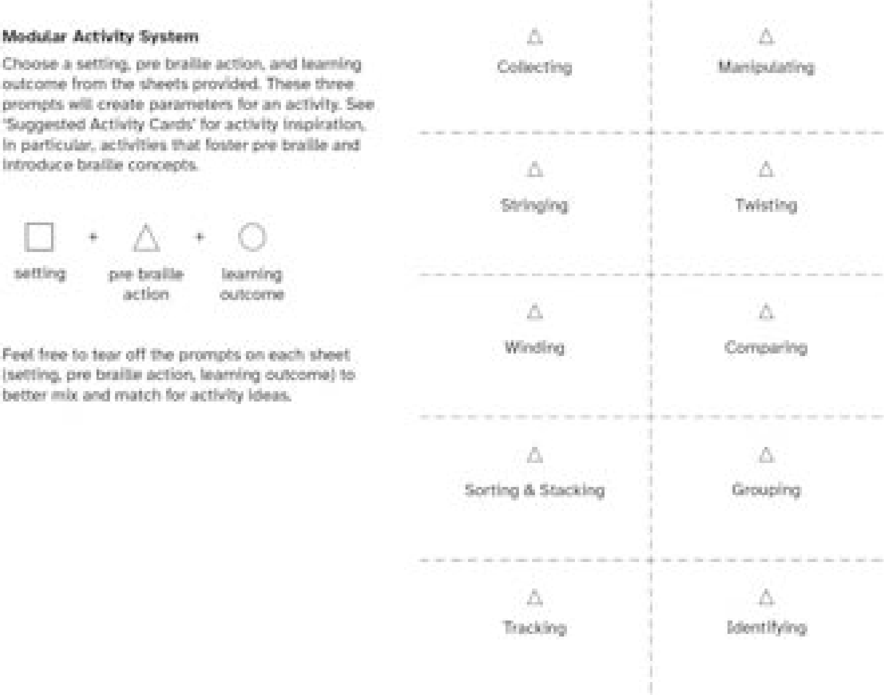
Notes:

Fig. 5 First version prompt cards (Graphics by the Author 2021). Alt Text *Card* A: A four by six inch card named Activity: Field Trip! Below the activity name is: suggested materials, the environment in which the activity should be done, and a list of seven steps. The steps outline how the activity should be completed. Alt Text *Card B*: The activity card continued (the backside). Two columns of text, the left describing the braille cell formation with an illustrated image. The right column describes the benefits of using an egg carton for braille cell comprehension. Below the text is an illustration of a six-piece egg carton. The bottom half of the card leaves space for teachers to take notes

Inclusive Considerations

It is important when designing for a marginalized group to ask: Is the product available? Does it function with ease? Is it feasible? Is it reliable? And are needs recognized and understood? Participants and I co-designed with kindergarten teachers in mind as the primary users. These users may or may not have students with sight loss in their classroom. Some of the families attending the school may be of low income; others may have children who are blind or are developing sight impairments. Designing for people outside of the majority demands different questioning and holistic thinking (Fig. 7).

The swatches above illustrate the color decision. High contrasting colors make the pouch accessible to students with various sight abilities (low vision, color blind, and sighted). The contrast allows for distinction between different sections and



Modular Activity System

Choose a setting, pre braille action, and learning outcome from the sheets provided. These three prompts will create parameters for an activity. See 'Suggested Activity Cards' for activity inspiration. In particular, activities that foster pre braille and introduce braille concepts.

Feel free to tear off the prompts on each sheet (setting, pre braille action, learning outcome) to better mix and match for activity ideas.

△ Collecting	△ Manipulating
△ Stringing	△ Twisting
△ Winding	△ Comparing
△ Sorting & Stacking	△ Grouping
△ Tracking	△ Identifying

Fig. 6 Second version prompt cards (Graphics by the Author 2021). Alt Text *Card* A: A card introducing the activity prompt system. This card includes a description of the system followed by three shapes, a square, triangle, and circle. Each shape corresponds to a prompt: setting, action, and learning outcome. Alt Text *Card B*: Two columns and five rows. Each section includes a small triangle followed by a pre-braille action, i.e., collecting

Fig. 7 Color: Fabric (Images by the Author 2021). Alt Text *Fabric A*: A close-up photograph of the tactile pouch. Specifically, a yellow pocket with a red button fastening sewn onto a deep denim blue fabric. Alt Text *Fabric B*: A close-up photograph of the tactile pouch digitally modified to black and white

Fig. 8 Color: Digital (Images by the Author 2021). Alt Text *Digital A*: A light blue square, a purple triangle, and a dark blue circle. Alt Text *Digital B*: The light blue square, purple triangle, and dark blue circle digitally modified to black and white

functionalities, although not crucial to comprehension, therefore, the pouch can be used by those who are blind.

The activity prompt system required similar color considerations. Three colors were chosen to distinguish between the setting, pre-braille activities, and learning outcomes. A colorblind-friendly color palette was chosen. The three colors are: a light blue, purple, and deep blue. Even when printed in black and white, this color palette is distinguishable due to high contrast between the three tones (Fig. 8).

Designed Outcomes

Proposed Tactile Pouch

From the co-designs, in particular with teachers of the visually impaired (TVI), we reached a slightly different pouch design layout. Early ideas and concepts arose throughout the interview process. Coming into co-design sessions, participants did not have any reference to early sketches and/or mockups I had done. It was only after they participated in an asynchronous activity and shared their thoughts and suggestions, that they saw the early mockups. The mockups then evolved, incorporating the specific needs described by participants, for example, a space to carry braille books. Early iterations only made room for a magnetic sheet. A new design allowed the same size pouch, 12 in by 16 in, to carry braille books of which are 11 in squared in size (Fig. 9).

So many tactile activities coincide with learning math concepts, such as counting, sorting, and grouping. In fact, the kindergarten classroom holds an array of centers, one being specific to sorting. In discussion with teacher participant H, a teacher of the visually impaired, the pouch encourages manipulation, having to look for objects in a pocket, then opening the pocket to play. Each pocket benefits from a different type of opening, i.e., button with string and magnetic clasp. With unique openings, the child will have to move their hands in different ways. Before the student has retrieved the objects from the pouch pockets, they will use problem-solving skills, determining how to access the objects, and then what to do with them once access is gained.

Understanding how to use zippers can be liberating for students with sight loss. The zipper is a difficult but necessary device to operate as it is something we encounter every day on clothing and accessories. Zippers will help students practice their finger and pincer strength. In addition to having a zipper on the tactile pouch,

Fig. 9 Proposed tactile pouch (Images by the Author 2021). Alt Text *Pouch A*: A dark blue cloth bag with two yellow pockets. Between the pockets is a zipper. The pocket on the left side of the bag is closed shut with a red button. Alt Text *Pouch B*: The backside of the dark blue cloth bag. Halfway down the bag is a rectangle lined with Velcro strips. A hand places one piece of fabric on the Velcro with Velcro sticker fastenings. Alt Text *Pouch C*: The blue fabric bag in full. On top of the yellow pockets are materials one might use to create tactile activities. The materials are: pipe cleaners, playdough, popsicle sticks, beads, and buttons

the activity prompt system suggests activities that help develop fine motor skills such as zipping and stringing.

The proposed tactile pouch holds a structured form allowing the depth for multiple books and objects to be stored. The opening of the pouch includes a toggle to pull and keep objects inside secure. The toggle is a tool that requires fine motor manipulation and finger strength. The front, in a dark denim fabric, has two yellow pockets, each with unique clasps. A zipper is placed between the pockets. Its function is solely to practice fine motor manipulation. Inside the pouch is a mesh pocket. The pocket holds a magnetic sheet that works in combination with magnetic stickers. A portion of the backside is lined with Velcro strips. The Velcro is effective in combination with Velcro stickers. The whole pouch is washable. This was important in considering the COVID-19 pandemic and the mess that comes with play.

Proposed Activity Prompt System

The proposed activity prompt system includes introductory cards of 4 in by 6 in, outlining what the system is, what is included, and how to get started. Cards of this size do not require a lot of space. They can be stored in a drawer, on a desk, or in one of the tactile pouch pockets. Following the introduction, are three 8.5 in by 11 in sheets (letter-sized paper), each listing ten prompts; ten settings, ten actions, and ten outcomes. These three sheets are intended to be cut out by teachers, stacking the prompts together with a staple, bulldog clip, or other fastening device. I suggest using a clip or ring, allowing ample flexibility, exploring all opportunities when mixing and matching the prompts. In addition to the three sheets, there is a card (4 in by 6 in) dedicated to demonstrating activity possibilities, matching eight settings, pre-braille actions, and learning outcomes. This can be referred to by teachers when planning class activities. The system takes these eight pairings one step further, with two detailed examples. The examples specify where the activity should take place, the types of materials the teacher might use, why the activity is important, and a list of steps to plan and construct. These specific examples highlight introductions to the braille writing system that might be discussed in class (Fig. 10).

The Ontario Kindergarten Program 2016 was especially helpful when constructing the prompt system, especially the pre-braille actions and learning outcomes. The Appendix located on pages 306–318 breaks down the overall expectations of kindergartners in relation to: belonging and contributing (BC), self-

Fig. 10 Proposed activity prompt system (Images by the Author 2021). Alt Text *System A*: Two hands hold and flip through the activity prompt system. The page shown illustrates example groupings, five settings, five actions, and five outcomes. Alt Text *System B*: The activity prompt system held together with a ring, lays flat on a blue background. Beside the system is six-piece egg cartons. Two of the divots hold stones. Alt Text *System C*: All parts of the activity prompt system lay flat on a blue backdrop. The grouping held together with the ring is beside the larger sheet of paper with learning outcome prompts ready to be cut out and clipped together. The ten action prompts have been cut out and grouped together with a clip

regulation and well-being (SRWB), demonstrating literacy and mathematics behaviors (DLMB), and problem-solving and innovating (PSI). The previous section was particularly interesting in regard to the action prompts. This section outlines multiple outcomes that relate well to pre-braille activities, i.e., "demonstrates control of small muscles, e.g., use a functional grip when writing, while working in a variety of learning areas, e.g., sand table, water table, visual arts area, and when using a variety of materials or equipment, e.g., using salt trays, stringing beads, painting with paintbrushes, etc." (Ontario Ministry of Education, 2016, p. 309). I urge teachers to reference the document, in particular the Appendix starting on page 306, when looking for additional outcomes for activity creations. The additional activities can be recorded on the blank cards provided in the activity prompt system.

Conclusion

Practicing tactile skills such as finger and hand strength, two-handed coordination, and fine motor development is especially important in an ever-evolving digital world. Literacy learning requires continuous reading and writing practice, but with technological advancements, students are using devices to assist their work at an earlier age.

I worked directly with kindergarten teachers and teachers of the visually impaired, listening and learning from their experiences, understanding what types of support and/or needs they require while teaching. Together, we used our knowledge on the importance of literacy learning and created a system that would assist kindergarten teachers engage students in pre-braille activities and introduce the idea of reading tactually. "Every child should feel that he or she belongs, is a valuable contributor to his or her surroundings, and deserves the opportunity to succeed" (Ontario Ministry of Education, 2016, p. 125). By introducing reading tactually, also known as braille, students become aware of other abilities, making the classroom a safe and inclusive space to learn and explore.

The project was only possible through multiple design iterations and co-design sessions required in participatory research methodology. Co-design, or co-creation, means listening to and learning from participants' experience. From there, assessing the needs and barriers that prevent something from being truly inclusive. This project built upon a need for a tool that is feasible, available, and fosters multiple modes of tactile engagement. Design iterations explored a variety of textures, vision-friendly color palettes, and flexibility in materials, spaces, and outcomes. I argue that with continuous tactile practice, in the form of pre-braille activities, students who need to later learn braille will benefit from this early exposure. It will also assist those new to the braille writing system and reduce stereotypes in the classroom.

Based on work with teachers, future research will look at the benefit of tactile and play-based learning in grade schooling, after kindergarten. Some teacher participants explained grade schooling, grades one and two, do not engage play and inquiry-based learning like kindergarten does. Students must make big changes in learning styles between the summer of kindergarten and grade one. This is especially concerning for students who learn kinesthetically. There is a possibility to reinforce the benefits and introduce pre-braille learning beyond the kindergarten classroom.

Limitations

As previously mentioned, the global COVID-19 pandemic of 2019–2021 made the Major Research Project process quite challenging. Going into schools and speaking with teachers was no longer an option, interviews and co-creation sessions were done remotely, and design feedback relied on visual and audio descriptions of what was being created. Gaining trust with people in person can be difficult, let alone in the digital space. The co-creation process of this project was altered to fit the teachers time and schedule, only appropriate for the mental and physical exhaustion that came with work and school moving to a fully online experience.

The proposed design outcomes are yet to be tested by participants. Teacher participants co-designed the initial system and offered feedback via emails and phone calls but did not have the time to test the tactile pouch and activity prompt system in the classroom. Only two pouches were made, and completed later in the process, therefore, could not be sent to all participants and in time. The activity prompt system could have been emailed to participants for them to print and test during class time; however, classes were conducted online at this time. Introducing a new and tactile system would benefit from in-person testing, especially when first introduced.

Recommendations for Further Research

This research demonstrated many opportunities and directions, some of which include: a sharing platform, opportunities to continue pre-braille learning and development outside of school months (summer), and conducting similar research with kindergarten students and their parents.

Teachers need to be intrinsically motivated to do their job, but support can always be increased. Support may look like extra assistance within the classroom, cooperation, and stronger communication between parents and teachers, a platform to speak with other teachers and share experiences, or more manipulatives and tools available in the classroom. I especially see an opportunity for further work on a digital platform or forum for teachers of the visually impaired (TVI) and orientation and mobility specialists (O&M) to share and assist one another.

Another area of interest and possibility is support for students with sight loss over the summer months, when formal school is not in place. A space and time to continue practicing their pre-braille activities in the months off school would be most beneficial. This could be in the form of a camp, summer classes, multisensory kits that could be used at home with parental assistance, etc. Instead of developing something new, there may be possibilities of working with or integrating this teaching into existing schools and galleries that host summer classes.

The tactile pouch is an inspiring piece. It provides an idea of the format, materials, and types of activities that can be used to foster pre-braille exercises and introduce the braille writing system. Using found materials throughout the co-creation and design process inspires a do-it-yourself (DIY) project, as readers reflect on found materials in their home or classroom to produce a pouch. With limited sewing knowledge, I was able to design something that could be recreated fairly easily. I enlisted some sewing help, but for those who have sewing knowledge, I imagine creating their own pouch would not be very challenging. Workshops encouraging the making process could be hosted by parents and teachers with sewing practice. Tactile pouches could be made for people with limited resources and/or experience. The tactile pouch workshop idea is borrowed from face mask DIY and workshops emerging out of the COVID-19 pandemic.

Parents are the first teachers of their children, and they have a lot to share with teachers, as I understand from my interviews. It would be interesting to conduct a similar research and co-creation process with parents of children in kindergarten. There is an opportunity to discover and address the parent's needs, in addition to improving communication between parents and teachers of students at the kindergarten level.

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Remote Co-design in the Digital Age

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Abstract

Co-design is used to provide a wide range of stakeholder perspectives before and during the design process, but geography and transportation difficulties often prevent important stakeholders from participating as co-designers. This chapter explores a spectrum of co-designs from group to individual and describes techniques that have been successful when working with co-designers remotely. Techniques for working with individuals with mental or sensory impairments, in particular visually impaired participants, are also given. Four examples of co-designs led by the authors are given with a discussion and tools used in each session. Incorporating remote techniques into the co-design process enables stakeholders from around the globe and those with mental or sensory impairments to provide feedback and input throughout the development process.

Keywords

Co-design, Inclusion, Remote, Virtual, Non-visual

Introduction

In 2008, Sanders and Stappers published “Co-creation and the new landscapes of design” which defined the term “co-design” as “the creativity of designers and people not trained in design working together in the design development process” (Sanders & Stappers, 2008). Sanders and Stappers describe how co-design contrasts with traditional design, in that co-design is designing for a purpose instead of designing a product. To achieve this paradigm, end users need to be brought in during the ideation phase, before money and time have been invested in a solution, and treated as equal to the main designers. “Professional” designers shift their role to be a facilitator and bring knowledge of what’s possible and how to get there to the process.

There are many techniques to facilitate co-design, both group based and individual, and Hendriks et al. (2015) recommend customizing the co-design methods to the participants. Lavender et al. (2020) conducted 27 in-person group co-design sessions with small groups, and each group utilized a toolkit to quickly prototype a solution. Santin et al. (2019) and Mäkelä et al. (2019) began with in-person group workshops, where stakeholders met and discussed aspects of the system as it was developed. They then did virtual one-to-one sessions with users to evaluate and get feedback on their prototype. Lee (2018) and Siu et al. (2019) performed individual co-design sessions with users where problems were identified, a prototype was developed, and then an existing prototype was shown to the user, followed by a debrief. During 2020, several design firms published guides on how to run virtual co-designs, but examples and guides are lacking in the academic literature (Castán, 2020; Ringrose, 2020). These are useful resources for running co-designs with an audience without physical or mental impairments and who are able to use a digital whiteboard. In the academic literature, Dorta et al. (2016) describe a promising virtual reality application they developed to facilitate co-design of physical objects, but no mention was made if the participants had any kind of mental or sensory impairments.

Hendriks et al. (2015) point out that many of the traditional ideas of ideation include verbal conversations, groups, drawing, writing on paper, crafting or moving objects, or viewing pictures. Virtual co-design sessions also may include virtual reality (Dorta et al., 2016). These methods are often not accessible for individuals with mental or sensory impairments. They recommend, rather than trying to develop a one-size-fits-all methodology to co-design, facilitators should structure activities and outcomes around participants with an initial co-design session to create techniques for future sessions.

One of the most impacted groups with traditional ideation and design techniques are non-visual participants. Metatla et al. (2015) described how the visual nature of many tools used conventionally for prototyping, such as storyboards, collaborative whiteboards, virtual reality drawing tools, and paper prototypes, makes them inaccessible to people living with visual impairments. Additionally, while using visual means to express ideas for designing graphical interfaces is appropriate, it is harder to use them to articulate the design of non-visual displays. The approach from Metatla et al. (2015) combined an initial stage involving focused discussions, application-independent technology demonstrations, and non-visual design activities, with a second stage comprising iterative participatory prototyping sessions that relied on highly malleable non-visual prototypes and audio diaries. They concluded that non-visual technology demonstrations allowed them to establish a baseline of shared understanding and to build a shared vocabulary for expressing non-visual design ideas, while low-fi physical audio-haptic mock-ups did not encourage co-design as anticipated and instead hindered communication. Participants switched to verbal descriptions to generate and capture design ideas instead. The use of highly malleable non-visual digital prototypes in the second stage provided an effective medium for shared design activities, while audio diaries expanded the users' reflection space to reach beyond design sessions and provided designers with a further resource of feedback. One of the challenges this chapter explores is how to develop prototypes and effectively present them in a way that can be facilitated remotely to non-visual users.

Many of the co-design practices revolve around in-person activities. With the increased globalization and acknowledgement for the need of greater diversity among co-design participants, in-person co-design is becoming too expensive and difficult for many situations. Remote co-design enables access to a greater number of participants who are often spread out geographically and difficult to physically reach. It also lowers the cost for both the facilitator and the participant, allowing more sessions to be held with the same budget of an in-person session. This chapter presents detailed examples of remote co-design sessions and discusses what works and what could be improved in each example.

Performing Co-design

Four co-designs are presented below showing a spectrum of approaches that worked and didn't work. After each description, there is a discussion that explores the effectiveness of the different aspects within that session. At the end, there is a final discussion that presents conclusions looking at all four examples and gives ideas for future sessions. Most of these studies were done during the last year, so are still pending publication. The first co-design uses a technical prototype in a group co-design session with six participants. The second example is a longitudinal multi-phase study that employs a mixture of surveys and individual sessions. The third example uses a set of tactile objects and sound files that were given to the participants before the group co-design session. The fourth example is a co-design session that was performed individually with participants.

Study 1: Group Co-design with a Technical Prototype over Zoom

Study Summary

In March 2021, our team held a co-design with six participants over Zoom where traditional group co-design methodology was utilized. The co-design was to investigate attitudes around traveling during the COVID-19 pandemic as a blind individual and to investigate some solutions to help increase confidence. There were six blind individuals from around the USA: three males and three females. The participants ranged from 19 to 82 years old with two participants between 18 and 30, one participant between 31 and 60, and three participants above the age of 61. One participant had low vision, one participant could see shapes, and the other four participants have no light perception or were totally blind. The co-design was approved by the institutional review board at the Smith-Kettlewell Eye Research Institute. Participants were compensated $90 for their participation. Rewards Genius ("Rewards genius," 2021) was used to pay participants, and consent forms were collected using Microsoft forms. To coordinate a time that worked for everyone, Doodle ("Doodle," 2021) was used. This study is pending publication.

Materials and Methods

The co-design was detailed in a facilitation guide that outlined each task, had links to all the relevant applications to install and use, and described the time set aside for each task. The six tasks on the facilitation guide were outlined as follows and were scheduled to take 1 h, but participants were told to expect 3 h to plan for technical difficulties. Participants received both individual email support before the session and three emails in the week leading up to the session, reminding participants to test an example application link that was given, fill out the consent form, install Zoom, get a note-taking device, and obtain headphones and a device with a keyboard and updated browser (needed for the prototype). Participants were also sent the facilitation guide the day of the session with links to the prototypes and Zoom session. Individual support was offered to help participants test their setup, although no one did more than ask for clarification over email.

- Warmup – 10 min: "Participants will be split into groups of 2 and put into a breakout session. Messages will be sent to each breakout room when the activity should switch. There will be a countdown when the activity is almost finished. There was a template to fill out: My partner's name is... They live in... List 3 of their favorite hobbies...."
- Reflect on relevant experiences traveling during COVID – 10 min: "Participants will be split into pairs and put into a breakout room, with a facilitation leader in each room. The facilitation leader will write down experiences in the google sheet. Reflect on a relevant experience. Using two items from the experience list below for inspiration and the relevant experience template, reflect on an experience relevant to the workshop's objectives: what worked and what didn't work about that experience? If you did not feel safe or independent during that experience, say why." There was then a list of experiences, such as shopping, doing outdoor cardio exercise, etc.
- Concept review and prototype – 40 min: "In this activity, participants will review two concepts and experience the prototypes. For each concept, participants will have time to review the concept material and capture any feedback in the space provided. After each concept review, participants will discuss their feedback. Facilitators will capture this feedback in the Google Sheet." There was then a detailed description of the two prototypes that were used, along with links to access the prototypes. Both prototypes were accessed through the web browser. Participants then had a list of questions, such as "Please write a list of features you like, and a list of features you dislike about the application." and "For the features you like, what did you like about them and why?". Participants answered questions for each prototype.
- Prototype generation – 25 min: "As a group, fill in the prototype build out template using the material from the previous two activities as ideation stimulus." Participants were then given a prototype template they needed to fill out that included problem, feature rankings, and final description of a product.
- Fill out prototype presentation template – 5 min: "As a group, fill in the presentation template. This resource will help focus your presentation to the key details of your work. Select one person to read out loud the presentation template."
- Group prototype presentations – 6 min (3 min for each group): "Each group will take 3 min to present, taking a few questions afterwards."

What Happened

The co-design session was completed with valuable insight being obtained, but the technical problems of groups and complex web-based prototypes on the computer meant that many of the activities needed to be modified.

- Warmup: The first technical problem came when Zoom groups did not each contain a facilitator after the Zoom Host split everyone into groups, and the interface was too complicated for the Zoom host to easily move participants, especially participants who had joined with a computer and phone, around the groups. This led to the warmup activity taking 35 min instead of 10 min and not everyone completing the task. Breakout rooms were not used for the remainder of the session.
- Reflect on relevant experiences traveling during COVID – 10 min: Originally, this was supposed to be done in small groups, but was modified to be done in a large group. Participants really enjoyed the diversity of perspectives in the large group, and the facilitator ensured everyone was part of the conversation. Despite being six individuals rather than two, the group was able to go through a number of experiences and talk about some experiences not in the list, such as the fear of racial violence while traveling as a blind person during COVID. This section generated extremely useful insights and flowed much easier than the icebreaker. The session took 45 min, instead of 10 min.
- Concept review and prototype – 40 min: This section began with everyone pulling up the email with the links to the online prototype. One participant's audio of the prototypes was streamed through Zoom and was too difficult to troubleshoot, so that participant muted him-/herself while exploring the prototypes. When participants opened the prototype, they needed to do three key commands to get the prototype working on their machine, and two of the participants experienced technical difficulties that needed to be resolved. One participant took 25 min to find the link to the first prototype, but when they were in the prototype, their cat unplugged their computer, and they had to get back into the prototype, which took them a total of 50 min. It took around 15 min for everyone but the participant with the cat to get the prototype working. Several of the participants had the prototype working in minute 1 and were just waiting for the other participants to get things working. There was no correlation between age or vision and getting the prototypes working. During this entire time, participants were all asking questions at once, and the facilitator had to keep track of where each user was in the experience while responding to their questions. The facilitator was able to ask several questions about the experience that were answered by the group, such as their thoughts on particular sounds. The facilitator also asked the participants to fill out the feedback form individually for the prototypes. At the 45-min mark, the participants switched to the second prototype. Everyone but the participant with the cat successfully switched from the first prototype to the second prototype within 3 min, and at 15 min, the facilitator moved to the next activity. In total, the prototype review session took 1 h and 5 min.
- Prototype generation – 25 min: At this point, the session was at 2 h and 15 min, and participants were getting tired. To modify this activity for a group, the facilitator asked what problem was the most important from the list from activity 2. Participants started with one idea, social distancing, then moved to other topics fairly quickly, and described solutions or ideas for how they would want to access information for several of the problems listed in activity 2. Many of the

discussions centered around the ideas in the prototypes, but the group was quick to move beyond the capability of the prototypes and outlined ideas that they would find useful. All participants contributed to this conversation. This section took 25 min, and at that point, the facilitator thanked everyone for their time and ended the session.

Discussion

This co-design produced some extremely useful insights, but took longer than expected and had several major technical difficulties that could have been mitigated with a different design. The sessions with participants sharing their experiences and discussing the prototypes were the most successful. This required little technical knowledge and is similar to other Zoom sessions for participants. The breakout rooms may have been useful, but for everything but the icebreaker, they were not really needed or worth the technical difficulties they caused. For larger groups though, the breakout rooms are a must. The prototype viewing session was the largest source of stress for everyone. The diverse technical support needs, even among technologically sophisticated users, made the group-based prototype experience extremely chaotic for everyone. A better design would include individual sessions with each of the participants to walk through the prototypes with them before the prototype discussion and prototype generation. This could either mean doing relevant experiences, and concept review and prototype individually with each participant, or having a short group session with relevant experiences, then an individual prototype review with each participant, followed by the prototype review and group prototype generation. Despite significant planning, technical problems are better mitigated completely, rather than attempting to lower the risk. Individual sessions would have allowed participants to get focused technical support and a more in-depth experience with the prototypes.

Study 2: Longitudinal Remote Methods for Needs Assessment and Formative Evaluation

Study Summary

We describe a longitudinal study to co-design auditory route overviews for previewing travel routes by blind people. The project was developed over four phases, from an initial needs assessment through several iterations of design and ending with a formative evaluation (Aziz et al. 2022). Zoom was used as the remote conferencing software for all virtual meetings.

Phase 1 was a remote survey, phase 2 comprised a series of in-person group co-designs combined with remote feedback on those designs, phase 3 was an in-person usability study, and phase 4 was a remote one-to-one co-design session. Consent was obtained by email in phases 1 and 2, while in phases 3 and 4, consent was obtained via an accessible form included in the software platforms specifically built for those studies. Participants took part voluntarily in the first two phases, while participation was paid through cash or direct deposit in phases 3 and 4 as those phases were much longer.

The target population (participants) were heavily involved in each phase. Most of the work was done with participants contributing online, with one phase taking place in-person. Some participants were chosen to contribute across multiple phases to add longitudinality and depth to the data. These participants experienced how the research evolved, providing input at multiple stages, having had time to think about the system and its issues in between the studies. Other participants were deliberately chosen because they hadn't been involved in previous phases and were able to bring a fresh viewpoint not influenced by the development process. In what follows, we describe the research methods employed and reflect on their efficacy.

Materials and Methods

We decided to administer the needs survey online in order to reach a more diverse range of potential users. It was important to make participation from people's homes or places of work as straightforward as possible and avoid unnecessary travel. The early part of the online survey focused on "what" and "why" questions, namely, "what is an auditory route overview?" and "why would a system to present such overviews be useful?". The second part of the survey focused on specific requirements for content: "How long should an auditory overview of a route be?" and "What different types of audio should it contain?". Fifteen blind participants from different geographical locations from Asia, North America, and Europe participated. The participants were aged between 17 and 72 ($M = 41.86$, $SD = 16.19$) years. The survey was designed on SurveyMonkey ("Survey monkey," 2021) and tested for accessibility using the JAWS screen reader. Participants were provided the link to the survey, which they accessed and completed in their own time.

Based on the outcomes of the survey, a design study was conducted, comprising two separate sessions: in-person designer workshops with design experts and remote formative feedback sessions with potential users.

The design workshops took place in person. The experts in the workshops designed example auditory route overviews and discussed them in semi-structured interviews. Three out of the eight designs from the designer workshops were chosen for the user feedback session on the basis of the variety in their techniques and content. These sample designs were distributed to blind participants in the formative feedback sessions which were conducted online through email. The sessions involved participants listening to the designs and responding to survey questions. The content of the questions was informed by the discussions in the earlier studies and focused mostly on the content and quality of the auditory designs. The majority of questions were open-ended to encourage discussion of ideas and preferences. Eight blind individuals, aged between 25 and 57 years ($M = 42.14$, $SD = 12.63$), participated in the study. Participants were encouraged to give detailed feedback. The findings from the design study led to the design guidelines on which a prototype system was developed.

The prototype system that was developed in the previous phase was then evaluated for usability using Lego blocks in an in-person laboratory study. A major reason for conducting this in-person was the experimental equipment. The disadvantage, however, was the limited number of participants. One way of doing this remotely would be to transfer it online. While this would require the development of bespoke software to emulate the experimental setup, it would have the advantages of increased participation, participant's ease due to being at home and performing the study on their own machines, and reduced stress from commuting to the lab. While some Lego simulation software exists ("Lego digital designer @ONLINE," 2019, @leocad), these would not fulfil the requirements for the experimental study. For example, the bespoke software would have to be accessible and would require the integration of Lego simulation and the auditory route overview system.

Six blind individuals, aged between 24 and 58 (M = 47.67, SD = 13.75) years, participated in the usability study. All participants were comfortable with independent travel and had at least 5 years' experience with computers. The study comprised two parts: (1) presenting participants with the auditory route overviews generated by the prototype system, requiring them to reconstruct the route using Lego blocks, and (2) user feedback through an end-of-study survey consisting of both ratings and open-ended questions. The data from the first part of the study and the rating questions were analyzed using statistical methods, such as ANOVA, while the qualitative responses were analyzed using thematic analysis (Braun & Clarke, 2006).

The usability study was designed on simple, purpose-built software that included the details of the study, a training module that allowed the participants to train on the design specifications at their own pace and provided the auditory route overviews for the reconstruction tasks in three separate trials. The study details and the initial briefing were provided through a video, embedded into the platform, to communicate the experiment instructions effectively and uniformly to all the participants. The routes presented in each trial were chosen randomly from a predefined pool to ensure that no bias was added to the experiment and a clean comparison within trials and between participants could be made.

In the final phase, an application-based usefulness study was conducted to investigate how the blind users utilized an interactive and customizable auditory route overview system to preview routes and make decisions regarding them. The study was conducted online using an accessible, custom-built, interactive web application. The design of the interaction on this platform, in terms of navigation and placement of buttons, was informed by the training platform of the previous usability study and was basically a second iteration of an accessible experimental portal. The application included the information regarding the study, a method to acquire consent, a training platform, the auditory route overview system, as well as the survey questions. The study was designed in a survey style to gather open-ended but focused responses related to the research questions. Further details were discussed in end-of-study interviews. There were four parts of the study. The first two required the participants to choose a route for a given task from a set of route options, while the remaining two investigated the retention and recall of route features. The data of the first two scenarios and the end-of-study interview was analyzed using thematic analysis, while that of scenarios 3 and 4 was analyzed using statistical techniques.

Eleven blind individuals participated in the study. They were recruited through social media groups, re-recruitment from the design and usability studies, and snowball sampling. The participants were aged between 38 and 66 (M = 53.45, SD = 8) years, were comfortable with independent travel, and had between 12 and 45 (M = 34.2, SD = 8.9) years of experience with computers and assistive technology. The study was conducted individually, on a one-to-one basis. All participants, except PWS2 and PWS11, performed the study synchronously, while these two performed it in their own time, due to logistic reasons.

All participants apart from these two did the study on their own, while the researcher stayed connected with them via Zoom to ensure smooth running and provide any support if needed. All participants took part in the end-of-study interviews which were conducted individually over Zoom.

Piloting of the purpose-built software platforms was critical to all design phases. This was to ensure that the software was accessible to blind users and to minimize the effort needed to navigate the study platforms. Both the usability and the usefulness studies had custom-built software, with the usability study having a physical Lego-based setup as well. The usability study was piloted twice with a sighted person and once with a blind person to ensure smooth and uniform functioning of the experiment. With the sighted person, the pilot was repeated to remove ambiguities and incompleteness of instructions and to confirm that the different routes were realistic (Cairns & Cox, 2008), while with the blind person, it helped ensure that the entire experimental setup was accessible and easy to use. The usefulness study was piloted twice with a blind user to ensure that all the interactions were understandable, that flow between the different web pages was smooth, and that the screen reader could access the entire website without any issues. Even after repeated piloting, some issues of accessibility still arose during the study, such as not being able to read the labels of radio buttons. This was anticipated, and so the study sessions were performed synchronously where possible, to provide support during the session.

What Happened

The decision to conduct all but one of these studies remotely turned out to be a good one. No issues were encountered with communications or with participants preemptively accessing and auditioning the auditory route overviews sent to them as email attachments. It was clear from the results of the initial survey that auditory overviews of routes were considered useful and important by the participants and that their design and duration should vary depending on the content being represented.

Some interesting and valuable results arose from the design study. The designers predominantly thought that the overviews should be abstract. They believed that overviews were supposed to be more metaphorical than literal. Furthermore, they thought an abstract auditory display might give quicker representation, while a literal description using only speech would require more time and cognitive load to process. These ideas were in direct contrast with the blind participants who considered functional information to be more important. This discrepancy is representative of the gap that can exist between expert designers and user requirements and is, in and of itself, a compelling argument for co-design.

An extreme example of this arose when some designers designed their auditory route overviews using only sounds. Blind participants felt that the sounds of landscape and points of interest (PoI) alone were useless for guiding travel and must be augmented with more concrete speech-based direction information.

During the process of consolidating the results of this study into a prototype design, the researcher had to take a position on this discrepancy. She decided substantially to take the viewpoint of the blind participants, as they represented potential users of the system and had substantial experience being consumers of auditory displays.

The comments from the participants and the trends in the collected data indicated that they learned the system design over multiple trials. The data showed a reduction in both the number of replays required to learn the route and the time required to reconstruct it as experience with the system increased. Moreover, participants reported increased confidence in recognizing and placing PoIs over trials. User input from this study led to major design changes to the developing prototype.

A key decision concerning the usefulness web study was to run it as a one-to-one session between the researcher and individual users. We believe this made a significant difference in terms of being able to provide individual, tailored support to users and helped maximize the useful information derived from individual sessions. In general, users were successful in performing the tasks using the web application and responded effectively to the survey questions.

Discussion

Throughout this research project, a user-led design approach was employed to determine design requirements. It was based on an iterative process involving cycles of requirement gathering, rapid prototyping, and user-based evaluations, aiming to determine design guidelines generated by the participants and hence suited to the target user population (Barrass & Vickers, n.d.). Throughout this work, the findings of one phase fed into the research criteria of the next to create a longitudinal design process, with user involvement at every stage. Various instruments including questionnaires, interviews, and focus groups were used at different phases of the research to collect auditory/video and text-based user data, which was then analyzed quantitatively and qualitatively to develop design specifications. All of these research mechanisms proved to be robust in the context of online user participation. It is only in the case of the usability study that specific challenges exist, documented in the "Materials and Methods" section, that make it difficult to deploy in an online setting. Even there, the development of accessible Lego simulation software, integrated with the research tools deployed, such as surveys or interaction logging software, could enable that part of the study to be conducted online. It is likely in such a scenario that gamification might be usefully employed to promote user engagement.

Study 3: Group Co-design with Digital and Physical Prototypes

Study Summary

Two co-design workshops were organized with the purpose of exploring the design space of data sonification narratives. Based on prior formative work, the research team wished to explore the combination of narratives and audio graphics as a means of creating a more engaging and usable representation for data on the web. All workshops were conducted online through the Zoom video conferencing platform and lasted approximately 90 to 120 min. Participants were compensated with an Amazon gift card (Siu et al. 2022). Six participants were recruited from around the USA, and the same participants participated recurrently in both workshops. All participant co-designers identified as blind and/or visually impaired and used screen readers as their primary AT. The median age was 26.5, SD = 17.9, and range = 40. Workshop #2 had five participants instead of six since one participant from the previous workshop was not able to attend.

Materials and Methods

Before the workshops, the research team met with each participant individually to explain the goal of the co-design workshops and answer any questions. Additionally, both physical and digital materials that were used to support different workshop activities were shared with all participants. Physical materials were mailed to participants; these included tactile graphics, tactile prototyping materials (e.g., Wikki Stix and pipe cleaners). Digital materials included the agenda for each workshop, background information, and sample datasets in both audio sonification and tabular format.

Workshop #1 focused on the brainstorming and ideation stages of the design process. The goals of the activities for this workshop were to encourage conversation around different available data representations (tactile, speech, and audio), discuss preferences and tradeoffs, and start to formulate a list of guidelines for when each representation was useful or preferred. Next, we briefly summarize the activities in the agenda of Workshop #1:

- Introductions and Ice Breaker: To facilitate sharing and conversation among participants, we began the workshop with introductions from each participant and invited participants to share any personal data-driven story or interesting dataset they had explored.
- Background: To start with a common ground for discussions, we briefly reviewed different data representations and concluded with a problem statement to frame the workshops.
- Brainstorming and Ideation: Participants individually explored different datasets through different modalities (physical or digital) and shared what they liked or wished from each in a group discussion. For the individual exploration time, participants were encouraged to think about the story behind the data and how they might share it with others. After individual time to engage with the data, the research team started the group discussion with guiding questions. This was repeated for three different datasets. Participants were encouraged to discuss what worked for each dataset probe and what could be improved by proposing alternative data representation prototypes and combinations of prototypes. Throughout the discussions between participants, the facilitator took notes and, after each discussion, summarized some of the insights for generating prototypes, and these were further discussed by participants.
- Break: One 5-min break was provided between discussions.
- Reflection: The workshop concluded with a summary of the main insights learned, open questions, and next steps for the next workshop. Participants were also encouraged to provide any feedback on the workshop activities itself.

Between Workshop #1 and Workshop#2, the research team generated prototype alternatives that were discussed in Workshop #1. Facilitators provided a summary of what was learned from Workshop #1 and answers to any questions that couldn't be answered during the workshop.

Workshop #2 focused on the prototype stage of the design process. Activities focused on critiquing the different prototype probes that were generated from Workshop #1 and proposing new changes. Next, we briefly summarize the activities in the agenda of Workshop #2:

- Introduction: We began the workshop by reflecting on what we had learned from Workshop #1 and what the remaining questions we had identified were.
- Prototype Critique: Facilitators shared the prototypes that were generated based on the design guidelines generated in Workshop #1. After listening as a group, discussion followed.
- Prototype Generation: Participants were asked to share prototype ideas for how they would use the design guidelines to create their own data narratives. Participants shared with the group and discussed.
- Reflection: The workshop concluded with a summary of the main insights learned and remaining questions. Participants were also encouraged to provide any feedback on the workshop activities itself.

What Happened

Most of the activities were followed by a group discussion which took longer than expected. At the same time, these reflection periods discussing the prototypes and suggesting new designs were the most successful in meeting the intended workshop goals. Thus, during Workshop #1, facilitators opted for entirely skipping one activity in order to allow more discussion time. Based on the learnings from Workshop #1, facilitators planned the timing of activities for Workshop #2 accordingly. Another tension during group discussions was making sure all participants were engaged and felt they could contribute. During different discussion periods, specific participants dominated the discussion, and with limited time, this behavior could easily leave out some thoughts from the quieter participants. It was helpful to start by doing a quick roundtable discussion where each participant shared one thought and then opened the floor to more open discussion.

Providing participants with all materials beforehand so they could familiarize and have them ready helped save time during the workshop and ensure all participants were ready to engage during the workshops. Additionally, providing participants with multimodal ways of accessing the same information helped accommodate for participants different needs and preferences. Participants could access the datasets used to guide discussions tactually, auditorily through sonification, textually, or through raw tabular representations.

Discussion

The research team was able to summarize design guidelines for sonification data narratives based on the prototypes and discussion during the two workshops. These were incorporated in an algorithmic solution for sonifying data interleaved with narration. An aspect that was very helpful throughout the workshops was providing participants with supporting materials beforehand in a variety of modalities so each participant could familiarize with the materials and access them in their own way.

The prototype activities were planned to last 35–40 min, but between sharing ideas as a group and allowing sufficient individual time, we found that having an additional 30 min of discussion time would have been a more comfortable pace. Unlike in-person workshops where participants can be discussing in small groups without interrupting others, online discussions demand engagement from all participants in the call. Breakout rooms could be one solution toward encouraging more informal discussions, but these add some complexity and reduce group collaboration. Despite using both physical and digital materials to support the session, the goal of the prototypes was for them to be entirely digital delivered through audio-based methods. For projects where the primary goals are investigating physical prototypes, further work will be needed to investigate how such prototypes can be shared and experienced by participants in multimodal ways through a remote format.

Study 4: Individual Co-design and Evaluation with a Technical Prototype

Study Summary

This was a virtual one-to-one co-design and evaluation session to create a method to represent geographical map data completely in audio. The co-design session was meant to determine past experiences, thoughts, and future designs around digital non-visual mapping tools. The result of this session was used as the foundation for future designs and funding for the project. The evaluation was reported in Biggs et al. (2019). All workshops were held over the Skype video conferencing platform, were recorded, and lasted between 1 and 2 h. There were ten participants who ranged in age between 16 and 43 years old, and participants were located in India, South Africa, Romania, Canada, the USA, and Iran. Participants completed consent forms using Google Forms. All participants had used a screen reader for at least 5 years and were congenitally blind. Participants were not compensated for their participation, and the study was approved through the institutional review board from OCAD University.

Materials and Methods

The study consisted of four sections: (1) an unstructured interview about the user's past experiences around navigation, maps, and technology usage, (2) a design session, (3) an evaluation of a prototype, and (4) a debrief and revisit of the design in section "Performing Co-design." Skype was chosen for its ability to easily share system sound which was critical for the monitoring in step 3, the evaluation. The prototype was built to run in the browser and required headphones, a modern web browser (Firefox, Chrome, or Safari), and a keyboard to use. Participants had the option to use a built-in text-to-speech engine or their own screen reader, and everyone chose to use their own screen reader. The sections were laid out to minimize bias with the researcher's preconceptions of the subject area. The interview consisted of open-ended and Likert scale questions, probing to discover if the participant had any issues with the subject area. If the participant had no issues, they would skip section "Performing Co-design" and move to sections "Study 1: Group Co-design with a Technical Prototype over Zoom" and "Study 2: Longitudinal Remote Methods for Needs Assessment and Formative Evaluation." A detailed description of the four sections is as follows:

1. Interview: The interview section began with demographic and health information and then moved into the participant's past experience. Initially, they were broadly asked about their experiences, desires, and feelings around maps and navigation. They were then broadly asked about their technology experience and usage. Finally, participants were asked their thoughts, experiences, desires, and feelings around "digital maps." Some examples are as follows: "What comes into your

mind when you hear 'digital map'?", "What kind of information do you wish you had from a digital map?", and "How would you like to interact with a digital map?". These questions were used to guide the user in thinking about their needs and desires around mapping and to get them warmed up to the topic.

2. The co-design began with the prompt: "Without worrying about feasibility or possibility, please describe what your ideal digital map experience would be." This prompt could have been overwhelming and a nonstarter, but since participants had already begun thinking about their needs and desires in section "Introduction," this prompt was not very overwhelming, although it still required some additional prompts to take shape. Participants were asked to first describe the system they wanted to have, and then they were asked to describe an experience using the system.
3. Evaluation: This section began with the researcher asking the participant to share their system sound. Since all the participants were screen reader users, this enabled the researcher to follow along with what the screen reader was saying to the participant and easily troubleshoot any issues. The participants were given a link over Skype to the webpage with the map viewer on it. First, participants were trained on the system by the researcher and explored the interface until they felt comfortable using the controls. Participants were then ask to complete a list of tasks, such as locate an object on the map, or describe the route between two objects. These tasks were evaluated by reviewing the recording after the session. Both participant responses and hearing the participant's actions over Skype were used to quantitatively score the tasks.
4. Debrief: Participants were asked about their experience with the prototype, how their thoughts on their ideal system in section "Performing Co-design" were influenced by the prototype, and what they liked, thought needed improved, and didn't like about the prototype and finally an open-ended "What other comments would you like to say about your experience?".

What Happened?

This co-design had very few technical difficulties and any issues were resolved during the session or the interview was canceled due to the inability to resolve an issue. One of the major problems was that Apple computers at the time were unable to share their system sound, so no participants with an Apple computer were able to complete the session. The prototype was also only available and working on a computer, so a number of older participants were unable to participate due to them not having a computer. Five possible participants were excluded due to not having a Windows computer.

1. Interview: This section gave the participant time to openly express their thoughts and feelings. Surprisingly, there was one participant who had no experience with maps, had no desire to experience a map, and didn't think maps would ever be useful. Other participants were able to express their feelings and experiences

around viewing geographical information for navigation and information analysis.

2. Co-design: One fear of the researcher was that participants would describe something that was too unrealistic and the results of this co-design would not be useful. But in reality, participants were often stuck picturing a system that was implemented into their past experiences, such as text descriptions. Participants also expressed worries that their ideal system would not run on the existing technology. The researcher reassured participants they could imagine anything without limitation and it just needed to be detailed and thought out. Four users wanted a full VR experience where they could hear their environment in 3D audio, feel objects and textures, and use their cane. Three participants described a refreshable tactile hologram that could expand to about an 11-inch square that would have a miniature of the location with them in the center. Two participants wanted an implant in their brain that would be super accurate and up to date that would allow them to just know where to go. One user found the idea of a digital map too alien to contemplate. Although these responses are pushing the edge of technical possibility, they provide a clear direction for future research.
3. Evaluation: None of the participants had major issues with viewing the prototype, although there were a few sound card problems, and some participants had to switch browsers. The researcher was able to troubleshoot in real time as the participant navigated the system. Some of the participants had problems finding the link on the Skype interface, so the researcher had to give them step-by-step instructions on how to find the link.
4. Debrief: Participants really appreciated being able to give their feedback after viewing the prototype. They collectively gave over 40 unique feature requests and described how this platform would impact their life if they had it for more locations. The final question that asked participants what else they wanted to share often presented some of the most useful insights to how the users would be impacted by a system (either the system they co-designed or the prototype itself). Participants felt open to share personal stories about times when they got lost or when their GPS led them astray.

Discussion

This co-design produced a significant amount of qualitative and quantitative data. The co-design produced around 15 h of interview recordings. One of the main cons of this study was that participants were unable to discuss and share their thoughts and ideal systems with other participants. The upside of this is that the systems that participants did describe in their co-designs were extremely detailed. The lack of technical difficulties meant that the entire session was completely focused on the subject area. It was critical that the researcher could hear the participant's screen reader, as this meant they could easily and quickly solve issues. The global nature of the participant pool also meant an extremely diverse number of perspectives were obtained across a number of cultures. One thing to note is that 15 h of interviews can be intensive to qualitatively code, so the coding technique should be chosen to account for this fact. Overall, the co-design and evaluation produced a significant amount of data with little stress. This co-design was completed with a $0 budget, but participants should be compensated when possible.

Discussion and Reflection

A number of observations can be made from the above studies that may be useful when designing future co-design sessions. One thing to note is that all the prototype outcomes of the above co-designs were digital experiences, so co-designs with a physical deliverable may need to adjust their techniques.

- Online needs more time: Studies 1 and 2 show that the online modality took much longer than expected due to several factors, including increased difficulty of splitting individuals into pairs and lack of control around prototypes. Study 4 required a significant amount of time from the researcher in both interviewing and analyzing the data. In general, it took around twice as long to accomplish the co-designs than expected.
- Online requires more coordination: All the co-design sessions required detailed planning and materials to be created, tested, and sent out before the session. The group co-designs each had a detailed agenda and had tested and insured technology and prototypes were in the hands of participants before the session began. All the studies had participants from multiple time zones, and coordinating across time zones is very challenging.
- Group co-designs need prototypes to be low tech, like tactile objects or audio files: The group session in study 1 had a complex technical prototype that was tested as a group. This was a disaster. Study 3 was much more successful when utilizing audio files and physical, uncomplicated objects. Study 2 mitigated the problem of showing technical prototypes in a group by showing the prototypes individually. The level of complication is probably relative to the population and maturity of the prototype, but it seems as if audio files are probably the most complex digital prototype that can be experienced as a group. This is because there are no questions about buggy computers or not understanding the interface that need to be troubleshooted in a group setting when using technology that is ubiquitous and familiar like a sound player. It also probably helped that study 3 met individually before the session to ensure the prototypes were ready and functional.
- Individual co-design sessions yield more data: Due to the more focused format, individual co-design sessions, such as those in study 2 and study 4, produce significantly more data than a group co-design. This is something to consider when planning how long a study analysis will take.
- It’s easier to do demos individually, but discussions are better done in groups: Studies 1 and 3 both found significant value in groups collaborating and talking among themselves, but the technical prototype was not good for a group setting.

Designing multiple sessions, similar to study 2, would allow for both group discussion and group collaboration while minimizing technical problems.
- Providing materials in multiple modalities was helpful: Participants desired to experience the prototypes and materials in the modality they were most comfortable with. Study 3 is the only study from this group that attempted providing multimodal materials, but it seemed to work well.
- Piloting and testing with users before the study can mitigate technological disaster. Both studies 2 and 3 performed significant testing with participants before performing the evaluation. This helped reduce possible errors and ensured the platform was accessible and understandable.
- Synchronous vs asynchronous: Study 2 found it was possible to run a prototype session asynchronously, and they also explored utilizing surveys as part of the co-design process. The problem with this method is that participants are unable to interact with each other. Responses to questions and follow-up questions also become more difficult when the researcher is not present. The advantage is the wider number of participants who can participate in the co-design.
- Payment across multiple currencies can be complicated: *Note:* The below are not recommendations by the authors, but have been used by the authors in the past. Also, functionality may have changed when this is being read. When designing a global study, being able to pay participants in their local currency is critical. There are several options: Rewards Genius ("Rewards genius," 2021) allows batch payment in multiple currencies with a nominal fee and allows participants to redeem their reward at over 80 popular locations, such as Amazon and Uber. Rewards Genius also allows the accounting department of an institution to provide a requested amount of money, and if that money is not spent, they will refund it to the institution. PayPal ("PayPal payouts," 2021) also allows for batch uploads of payments, although recipients need a PayPal account. Amazon ("Buy gift cards in bulk for your business – amazon incentives," 2021) is another popular option that allows for batch uploads of rewards cards in multiple currencies. The cons are if Amazon is not in the user's location and if the user does not have an Amazon account.

Co-designing is critical to achieve the paradigm of designing for a purpose, rather than designing a product. Having access to participants from around the globe and with diverse perspectives requires the use of remote technology and techniques. The studies outlined in this chapter present a set of resources, methods, and experiences that can be utilized in future remote co-design sessions as part of an inclusive design process.

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Cocreating Inclusive Interviews: VR Technologies for Job Interview Training of Individuals on the Autism Spectrum and Strategies for Employers

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Mirjana Jevremovic

Contents

Abstract

This is a report on the research of how to use Virtual Reality (VR) technologies and Video Self-Modeling (VSM) techniques to structure job interviews so that individuals on the autism spectrum could more easily provide the information that employers seek. The report also addresses the use of the same technologies for job interview training by informing the affordances of a different structure of behavioral interview questions. The participatory research comprised two phases, Phase 1:

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codesign development and deployment, and Phase 2: codesign evaluation and revision. It was rooted in an iterative and inclusive process that generated an app with a scaffolding sequence of behavioral interview questions to address different verbal abilities of individuals with Autism Spectrum Disorder (ASD). It resulted in the creation of strategies for employers such as the Inclusive Interview Guide for Employers and specific question inputs. This cocreative method generated technologies and procedures that could be used by individuals on the autism spectrum, as well as by employers, employment agencies, and ASD support programs. It demonstrated a process by which to communicate better with individuals on the autism spectrum.

Keywords

Autism · Codesign · Inclusive interviews · Scaffolding questions · Virtual reality · Video Self-modeling

Introduction

A critically important part of our current hiring system is the job interview. Unfortunately, this step is often inaccessible to individuals with disabilities especially those on the autism spectrum. Individuals on the autism spectrum are often disadvantaged in job interview scenarios where social skills and verbal expression may be prioritized over areas where individuals with autism have greater strength such as focus and tenacity. Additionally, job interviews generally consist of behavioral, situational, and job-specific segments (Structured Interviewing, n.d.). As individuals on the autism spectrum struggle with generalization, the behavioral component of the job interview is considered the hardest.

This participatory research tried to discover, with individuals on the autism spectrum as cocreators, the best way to help address challenges of behavioral interview component. The result was a nonimmersive Virtual Reality (VR) app that provides opportunity for job interview practice while scaffolding structure of behavioral questions makes them more specific and easier to answer. It allows individuals with different verbal and cognitive abilities to use an app successfully and provide more information about themselves. The research gave insights into ways to conduct job interviews more inclusively and opened pathways for more inclusive employment structure where employers, employment agencies, and support organizations can all benefit from the results. We gained some answers on how to adjust job interviews that in its current form represent the major systemic barrier to employment of individuals on the autism spectrum.

ASD and Employment Rate

The National Autism Spectrum Disorder Surveillance System (NASS) was Canada's first national-level surveillance-system to register all the individuals affected with

ASD. NASS' findings revealed that 1 in 66 children and youth were identified as being on the autism spectrum (Autism Ontario, 2018).

ASD can be defined as a lifelong neurological difference that affects a person's behavior, communication, and social interaction. It influences how a person perceives and interacts with the world around them (Autism Ontario, 2018).

Furthermore, many individuals on the autism spectrum have additional co-occurring disabilities (87%), with a learning disability being the most common. These concomitant issues may be contributing factors to 67% unemployment rate reported by Canadian Survey of Disability of 2017 (Government of Canada, 2020).

As per Huffcuff (2011), the analysis of the employment interview construct literature shows that "the twin interpersonal constructs social skills and verbal expression appear to have some of the strongest correlation with interview ratings" (Huffcuff 2011, 74). Individuals on the autism spectrum struggle with interpersonal and communication skills, which would result in a low interview rating despite their educational achievements and qualifications for the position. For a person on the autism spectrum, job interviews are very challenging.

Therefore, addressing the challenges associated with job interview became the focus of the research, with an emphasis on the use of behavioral questions. This research aimed to explore the following: VR app as a means for job interview training; the structure of behavioral interview questions; and ways to apply these two approaches more inclusively. The cocreation process of development, deployment, evaluation, and revision was done by all parties involved, participants and researchers alike.

Employment Initiatives

There were many successful vocational training programs implemented during secondary education for individuals with ASD (Wehman et al., 2014) but not many for adults on the autism spectrum. Due to a high unemployment rate, the Canadian government launched the Blueprint for National Autism Spectrum Disorder Strategy (the Blueprint) along with a substantial fund release (the Fund). The Fund dedicated 9.1 million dollars over 5 years to support innovative community-based projects designed to help individuals with ASD (ages 15–29). It included five action areas, one of which was employment. The program that resulted from these initiatives was Worktopia, a program offered by the EmploymentWorks Canada Centre. Worktopia is part of the employment action area, providing preemployment training for young adults on the autism spectrum. Through this program, individuals with ASD learn to define their goals, deal with workplace challenges, and practice the communication and social skills necessary for future employment (Chowdhury, 2017).

The Spectrum Works Autism Job Fair in 2019 proved that there has been an increase in employers' awareness of the abilities of people on the autism spectrum (Simmons, 2019). In a similar vein, there is Specialisterne Canada, an employment agency that focuses on employment strategies for individuals with ASD who have completed higher education within the IT industry (Specialisterne, 2013). However, despite the rise in initiatives and programs such as the one run by the Dan Marino Foundation – and many new employers open to hiring individuals with ASD – the unemployment rate for individuals with ASD is still extremely high.

Virtual Reality (VR) Benefits

There were not many studies exploring VR in the context of challenges related to job interview performance of individuals on the autism spectrum. The wider scope of literature review was conducted to better understand how individuals on the autism spectrum embrace nonimmersive VR technology and learn using these tools.

Most studies of VR as an educational tool were done with children on the autism spectrum. VR technology helps children with ASD improve their contextual processing and cognitive flexibility (Wang & Reid, 2013). Therefore, if a VR environment is carefully designed, it can provide students with more accessible contextual learning (Lan et al., 2018). The customizable aspect of VR environments allows for creating various domains where parameters could be adjusted as per each individual's needs. Garland et al. (2012, 511) emphasize the importance of this individual adjustment, referring to it as "instruction delivered with high fidelity implementation." The flexibility of VR, where steps could be repeated as many times as needed, allows for the degree of autonomy required by each learner since children, who are the same as adults with ASD in this regard, "follow their own agenda when learning" (Hentschel & Lange-küttner, 2019, 191).

Like children, adults with ASD benefit from the flexible options inherent in VR to accommodate their individual needs and unique learning styles. White et al. (2019) suggested that this customizable aspect of VR interventions benefits students in higher education. Articles published in the *Journal of Autism and Developmental Disorders* explore using VR to treat fears and phobias in individuals with ASD by way of cognitive and behavioral interventions (Maskey et al., 2014). Some articles point to VR as social imitation learning (Simões et al., 2014) and social cognition training (Yang et al., 2017). VR's adjustable features allow simulation of environments in which complexity is reduced, thereby enabling ASD individuals to learn social skills, social cognition, and social functioning (Kandalaft et al., 2013). Individuals with ASD experience VR environments as "safe to explore social risk-taking" (Gallup & Gallup, 2019, 226).

VR Job Interview Training and Video Modeling (VM)/Video Self-Modeling (VSM)

Although many studies show the benefits of VR for individuals on the autism spectrum, only a few have dealt with VR job interview training (Strickland et al., 2013, Smith et al., 2014, Burke et al., 2017.)

Strickland et al.'s (2013) study comprised a number of components including online training; role-play interview sessions for a hypothetical position; one VR job-training session including feedback; and repeated role-play interviews to measure performance improvement. The VR session consisted of two avatars: an interviewer and an interviewee. However, the avatar interviewer was led remotely by a clinician, and the participants had only one VR session and no opportunity to rehearse. The VR session where the avatar interviewer is led remotely by a person represents the main difference between Strickland et al.'s (2013) study and the studies by Smith et al. (2014) and Burke et al. (2017), namely, that Smith et al. (2014) and Burke et al. (2017) used humanoid avatar interviewers. Smith et al. (2014) also had role-play interviews as a baseline and an e-learning module with resume building. The VR program in Smith et al. (2014) study randomized 1000 questions and selected them based on participants' resumes. The VR feature also included a *coach* function to help participants with responses. There were 2000 ready answers that the coach would offer participants if they needed help. The Burke et al. (2017) study included one baseline VR session, four practice VR sessions, and role-play interviews. Although all the studies reported improvements in participants' performances, Strickland et al. (2013) and Smith et al. (2014) used role-play interviews for hypothetical positions, and participants in Burke et al.'s (2017) study had 14-week training with embedded curriculum for a particular job position and interview process.

Although these studies offered participants help with answers either in the form of a coach avatar (Smith et al., 2014) or educational training (Burke et al., 2017), they did not explore alternatives for interview questions as this research intended to do. Additionally, none of the studies included participants in the development process or in conducting the data analysis. Along with VR, video modeling (VM) and video self-modeling (VSM) were also explored as additional techniques to be included in the research to help participants with challenges of job interview training. Video modeling (VM), which is when individuals watch a video recording of someone performing a skill in order to learn that skill, is considered an effective way to facilitate learning in individuals on the autism spectrum (Fitzgerald et al., 2018). Video self-modeling (VSM) is when individuals watch a video recording of themselves and learn how to change something in their performance. The use of video recordings (i.e., VSM) is regarded as a supplementary tool to VR to provide feedback and allow users to take self-correcting measures pertaining to supplemental aspects of the interview process such as posture, eye contact, etc. (Burke et al., 2017).

Interview Questions

Job interviews usually consist of behavioral, situational, and specific job components (Structured Interviewing, n.d.). The behavioral element seems to be the most difficult for individuals on the autism spectrum because of the broad nature of behavioral interview questions. Some of the research literature suggests considering volunteering and school experience as transferable skills, since individuals on the autism spectrum usually do not have a lot of work experience (Autism Speaks, 2013; Fraser, 2016). Fraser (2016) also suggests rewording questions to be more experiential.

Additionally, each interview should consist of questions regarding fundamental skills, personal management skills, and teamwork skills (Employability Skills, n.d.).

Nowack (n.d.) confirmed the importance of these components in his *Personality View 360: Structured Behavioural Interview Guide.*

Purpose of the Study

The unemployment rate of 67% for persons with ASD demonstrates that traditional hiring approaches are not favorable to individuals on the autism spectrum. The ongoing communication challenges affect their prospects of employment. The main factor in getting a job is a powerful job interview performance. It is difficult for an individual on the autism spectrum to realize a successful job interview performance despite their talents and qualifications for the position.

The recent employment initiatives demonstrate the new direction that is being taken to support individuals on the autism spectrum to be successful in gaining employment. However, very few of these initiatives prepare individuals on the autism spectrum for a rigorous interview process. VR environments are beneficial to individuals with ASD because of their customizable nature, the possibility of realistic simulations, and the opportunity for repetition of the trials until the task is mastered. There are not many VR simulations of job interview training, thereby leaving a significant gap in the literature and a need for further research. Contrary to the existing VR job interview studies, I wanted to explore with this research *behavioral interviews* and *broad interview questions* using a nonimmersive VR app. In consultation with others interested in these issues, I tried to answer the following research questions:

1. How can VR/VSM technology be used for job interview training of adolescents and adults with ASD?
2. How can the same technology be used to structure job interviews so that individuals with ASD can more easily and better provide the information employers seek?
3. What are the affordances of the different structures of behavioral interview questions?

In conducting this research, my highest priority was that it be participatory research, where participants were included in all the cocreation process phases: development, deployment, evaluation, and revision.

Research Design: Cocreating Inclusive Interviews

Methodology

The *quality* or well-done, meaningful, and useful research involving individuals on the autism spectrum is based on person-oriented ethics, including individualization, acknowledgment of the lived world, empowerment in decision-making, respect for holistic personhood, and a researcher-participant relationship (Cascio et al., 2020). As an individualization segment, this research included an assent form with simplified language; an option for text on the screen during semi-structured interviews; visuals for all the prototyping; and optional support (one participant had a support worker). This research acknowledged the lived world of participants by inviting parents and significant others who play an important role in their lives/world to view video recordings and provide feedback. The participants' session schedules and changes were respected and accommodated. Additionally, I, as a researcher, shared with participants my lived experience, disclosing that my interest in the topic came from having a son on the autism spectrum. As participatory research, participants were involved in the codesign process of development, deployment, iterations, and testing the prototype, rooted in an iterative and inclusive process shown in Fig. 1 (participants were involved in all iterations except cycles 8, 14, and 15).

The biggest challenge in conducting quality participatory research is power-sharing (Nind & Vinha, 2014; Hagen et al., 2012; Reason et al., 2012). Additionally, there needs to be trust and openness to address the power imbalance. Therefore, participants were invited to share their interests and participate in discussions other than a research topic to facilitate trust-building. They talked about the love of singing, and online games, and shared their Anime work. They were shown respect

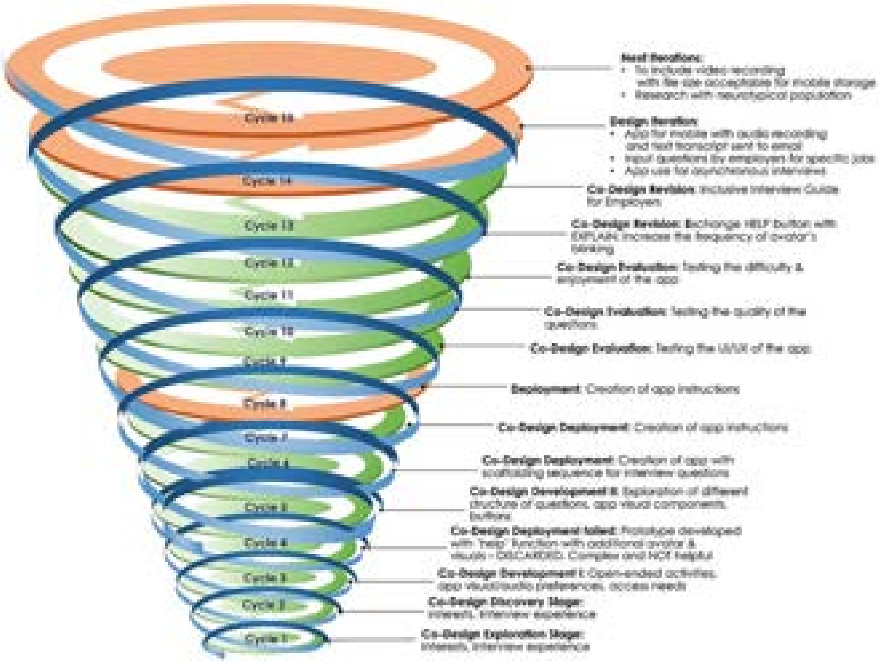


Fig. 1 Virtuous Tornado: design iterations of the inclusive process of the research

as individuals, not only as research subjects. The honorarium was mailed to each participant with a personalized message to express gratitude for their participation, and follow-up confirmation of their receipt of it was done via email.

All the participants, stakeholders, and stakeholder organizations will continue to be included in the dissemination of the results. The accessible format will also be provided to all the parties (see Appendix A). It represents the final segment of the person-oriented ethics that this study strived to achieve.

Method

Ethical approval for the research was received from the Research Ethics Board at the OCAD University, Toronto, Ontario (Ethics Approval Number 2020–2052). The research consisted of Phase 1: Codesign development and deployment; and Phase 2: Codesign evaluation and revision. The purpose of Phase 1 was to allow participants to share experiences and to explore visual and audio preferences and accessibility features that would inform the following prototype. Phase 2 was the process of analysis, during which the app went through an iterative process.

Participants

There were two participants in Phase 1 of the study (P1, P2) and three participants in Phase 2 (P2, P3, P4). One individual who participated in Phase 1 (P2) expressed an interest in being part of Phase 2, for which she signed a separate consent form. During Phase 1, assent and parental consent were obtained as participant P2 was a minor at that time. At the time of Phase 2, the same participant reached adulthood and signed a consent form. Therefore, P1 and P2 were the participants in Phase 1, while P2, P3, and P4 were participants in Phase 2.

Participants in Phase 1 were recruited through community organizations. P1 came from a special-care facility for adults with complex needs. P2 was recruited through a local community-based center delivering a social development program for young adults with intellectual disabilities, including ASD. Participants P3 and P4, who were part of Phase 2, were recruited through a consulting-service organization that provides solution-based assistance to individuals with ASD. The recruitment poster was included in the quarterly newsletter of the consulting-service organization.

All the participants were identified as on the autism spectrum and were older than 16, which constituted inclusion criteria. Additionally, participants had to satisfy technology requirements to be part of the study, which had to be conducted online due to the pandemic. Participants had to have a laptop or computer with a camera and Internet access. One participant (P3) was acquiring a new laptop, so she used her mobile phone instead for all the sessions.

Participants asked that their first names be used, so, going forward in this chapter, I will refer to them by their names (Table 1).

Table 1 Participant identifier-name description

Identifier	P1	P2	P3	P4
Name	Shemar	Christina	Olivia	Nicholas

Phase 1: Codesign Development and Deployment

Phase 1: Process

Phase 1 of the research consisted of four sessions. Each session was 30 minutes long. For each session, an email was sent containing the link for a Microsoft Teams meeting (video conferencing tool). Sessions were conducted using screen sharing function in Microsoft Teams. The researcher shared content with participants, and they provided verbal responses. All sessions were recorded with participants' permission. The prolonged recruitment process, timing, and scheduling conflicts resulted in separate codesign sessions. One individual attended all four sessions; the other participant could do two merged sessions at once (duration – 1 h). This combined session could not be recorded due to technical difficulties, so it was treated as an observation and data extracted from extensive notes taken during the session. After the last session, participants were thanked and offered an honorarium of a $20 gift card. Shemar had a support worker present during the session.

Session 1 and 2 with the first participant were part of exploration stage. They were conducted as semistructured interviews, supported with text displayed on PowerPoint slides. The purpose of these first two sessions was to provide insight into participant's interests, online activities, volunteering or job experience, and volunteering or job-interview experience.

Session 3 was part of discovery stage where participant was invited to draw upon their experiences that were enjoyable or considered successful in an effort to discover a way to clarify interview questions for the app development. Questions for this session were formulated based on participant's answers from the first two sessions. Session 3 was conducted as semistructured interviews supported with text displayed on PowerPoint slides.

Session 4 included prototyping with open-ended activities where the participant explored the app's visual and audio aspects, such as avatar, setting, and voice (i.e., computer-generated vs. human). For participant 1, the app included an accessibility feature: closed captioning as well as a help option with or without a robot avatar. The help option provided more specific questions that were supported with visuals to clarify the broad interview questions (shown in Fig. 2). However, the help robot avatar feature was added to the complexity and was not effective in the provision of help. It was reconsidered, and a new approach was explored with the second participant.

The second participant of Phase 1 explored the different help feature that had subquestions to help explain the main behavioral interview questions. He also rated the difficulty of the questions, as shown in Fig. 3. The session's result demonstrated that if the participant needed help, they would select the "help" button, which would lead to a more specific question, requiring a short "yes" or "no" as an answer. After having selected either "yes" or "no," the participant would be prompted to answer an

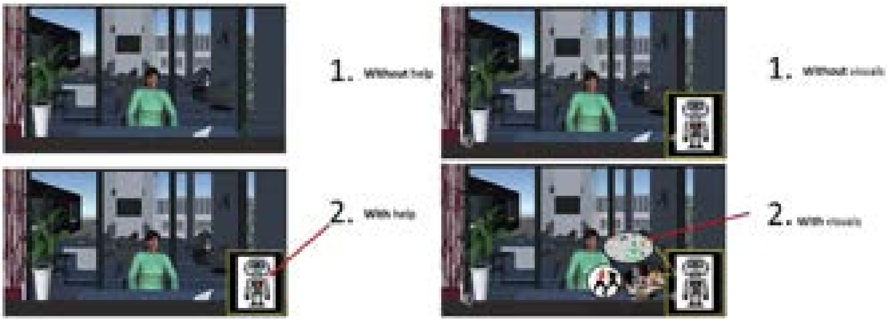
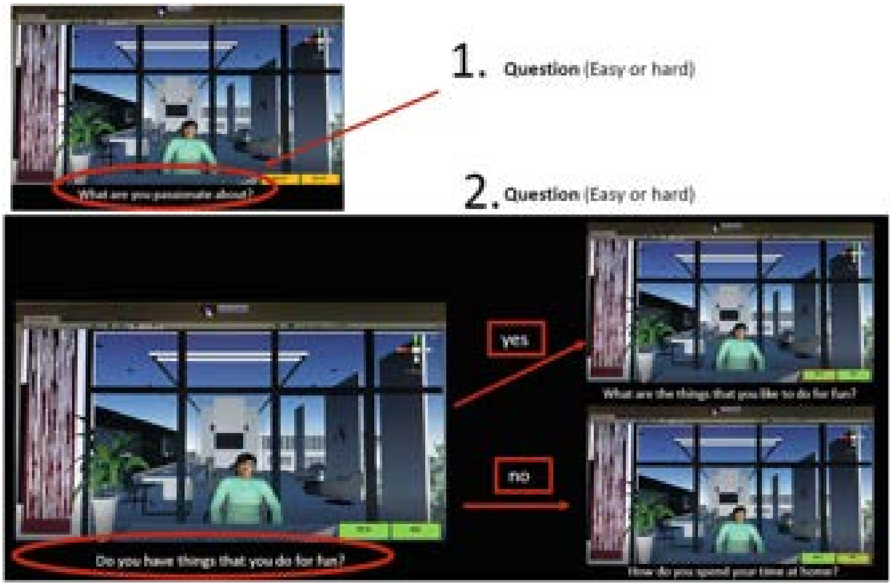


Fig. 2 Exploring the idea of help avatar (robot) with supporting images



What are you passionate about?

Do you have things that you do for fun?

What are the things that you like to do for fun?

How do you spend your time at home?

Fig. 3 Exploring the different structure of the behavioral questions

additional question. The improved help function provided the scaffolding sequence for each interview question. It was more efficient as the questions were more explicit, and easier to answer, and encouraged the participant to provide more information.

Phase 2: Codesign Evaluation and Revision

Phase 2: Process

Phase two was comprised of four individual sessions, and each session was 40 min long. Three participants were codesigners in Phase 2 of the research (one from phase 1 and two new participants). At the end of each session, participants were invited to draw from their life experiences not related to the research as topics for discussion. The discussion was on a voluntary basis, intended to demonstrate that participants were valued as individuals, not only as research subjects (Cascio et al., 2020). The discussion prolonged most of the sessions, with a maximum session duration of 2 h. In the end, participants were thanked for their participation and offered a stipend of a $50 gift card.

Findings from Phase 1 informed nonimmersive VR app creation using Unity game engine with total of ten main behavioral questions. There were three questions per session for Sessions 1, 2, and 3, and one question for Session 4. The end of Session 4 was left open for final comments and closing remarks.

This general session-plan was modified and depended on participants' dispositions at the time of the session. All sessions were conducted through screen sharing in Microsoft Teams. At the beginning of Session 1, participants watched a short instructional video on using an app. As shown in Fig. 4, the instructional video consisted of slides. Since participants did not have direct access to the app, they had to declare which button they would like to select, and the facilitator would carry out the task. For each question, a closed caption was displayed. It remained on the screen until the individual was ready to move to another question, allowing participants to reread the question and process the information at their own pace.

All sessions in Phase 2 consisted of three main activities:

1. Answering the questions
2. Responding to the survey
3. Analyzing the quality of the questions

Fig. 4 Instructional video slides

Answering the Questions

During the first activity, participants engaged with an app and committed themselves to providing answers to behavioral interview questions. If they knew the answer to the question, they would ask for the “finished” button to be selected, and the app would randomly choose another of ten main questions. If the participant did not know the answer to the question, they would ask for the “help” button. It would lead them to the more specific formulation of the same question, to which they could reply with “yes” or “no” as shown in Figs. 5 and 6. Each of these replies would lead to an additional explicit question (see Appendix B).

Responding to the Survey

After participants finished the first activity, they would respond to the Evaluation Survey shown in Fig. 7. In this survey, participants were asked to rate the session’s

Tell me about the time you worked in a team.

Did you ever work in a team at school, volunteering job, or a real job?

How did you like working in a team?

Do you like to work with people?

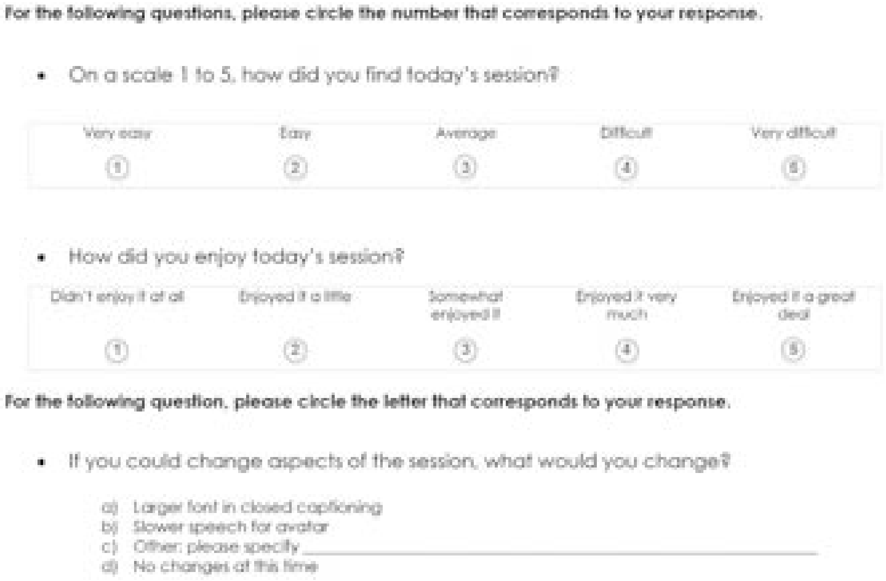
Fig. 5 App question no. 2 interface: scaffolding sequence

Fig. 6 Representation of scaffolding sequence for question no.2

difficulty from 1 to 5 using the Likert-type scale (Joshi et al., 2015, 398). Similarly, they were asked to assess their enjoyment of the session on a scale of 1–5. Next, participants were asked to note their assessment of the app and propose any adjustments to it (such as visual, audio, or any other of its features) or choose an option which indicated no proposed modifications to the prototype.

Analyzing the Quality of the Questions

For the last activity, the facilitator would use screen sharing and PowerPoint slides to display the text questions. Questions were shown one by one in the order the participant had been presented with them during the first activity. Each question was presented in its entirety of scaffolding stages (sample question 6 shown in Fig. 8). There were "main," "help," "yes," and "no" questions, representing four stages in the scaffolding sequence. Participants engaged in the analysis of the quality of each of the questions. They were asked to provide suggestions on improving each



For the following questions, please circle the number that corresponds to your response.

- On a scale 1 to 5, how did you find today's session?

Very easy	Easy	Average	Difficult	Very difficult
①	②	③	④	⑤

- How did you enjoy today's session?

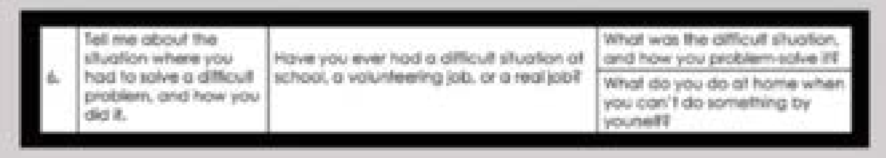
Didn't enjoy it at all	Enjoyed it a little	Somewhat enjoyed it	Enjoyed it very much	Enjoyed it a great deal
①	②	③	④	⑤

For the following question, please circle the letter that corresponds to your response.

- If you could change aspects of the session, what would you change?

  a) Larger font in closed captioning
  b) Slower speech for avatar
  c) Other: please specify ____________________
  d) No changes at this time

Fig. 7 Evaluation Survey Components



6.	Tell me about the situation where you had to solve a difficult problem, and how you did it.	Have you ever had a difficult situation at school, a volunteering job, or a real job?	What was the difficult situation, and how you problem-solve it?
			What do you do at home when you can't do something by yourself?

Fig. 8 Sample question 6

question's structure, to define if questions were easy or hard to answer, and to propose alternatives to make the questions more explicit.

Data Analysis

All sessions were video-recorded using a web camera, a part of the Microsoft Teams videoconference tool platform. The exception was Shemar, who did two merged sessions that could not be recorded due to technical difficulties. All the information collected from this participant was recorded in the notes, and this data was treated as observation. Video recordings were transcribed using Dragon Professional speech recognition software operating from the PC, ensuring the confidentiality and security of the data. The researcher manually adjusted transcripts to match verbatim the video-recordings' content. The text segments of the transcripts were treated as codes. Data coding was conducted using NVivo for Windows Qualitative Data Analysis software. Data were analyzed using an iterative and inductive approach, identifying patterns of meaning that came up frequently to inform themes. The themes that emerged were reorganized with further iterations. The final result was the identification of the following themes:

1. Interview Quality
    1a) Technology- app
    1b) Video Performance Feedback
2. Questions- Scaffolding Affordances
    2a) Question Creation
3. Communication

The first theme that appeared was the Interview Quality theme. Technology- app and the Video Performance Feedback were closely linked to it. All three themes correlated with the first research question. Theme 1 indicated how VR/VSM technology could be used to structure job interviews so that individuals with ASD can more easily and better provide the information that employers seek. Themes 1a) and 1b) related to the ways VR/VSM technology could be used for job interview training of individuals on the autism spectrum.

The themes of Questions- Scaffolding Affordance and Question Creation were associated with the second research question that explored affordances of the different structure of behavioral interview questions.

Theme 3 was a part of a broader category of secondary themes, out of which communication provided the wider social context for this research. It is an overarching theme, connective fibers that bind segments of this research to society as a whole. It demonstrates the need for and possibility of this inclusive matrix.

Each theme is schematically represented by a theme concept map shown in Figs. 9, 10, 11, 12, and 13. The theme concept maps demonstrate the process of qualitative analysis. They reveal data that were assigned specific codes, which, in turn, were grouped into nodes with similar properties. Nodes with similar attributes

Fig. 9 The concept map for Theme 1. Interview quality

Fig. 10 The theme concept map for Theme 1: a) Technology-app

Fig. 11 The theme concept map for Theme 1: b. Video performance feedback

Fig. 12 The concept map for Theme 2. Questions- Scaffolding Affordances

were further classified into subthemes. A few subthemes constituted each theme. The legend for the schematic representation of the categories is shown below each illustration (categories: theme, subtheme, node, and code).

Interview Quality

The first central theme that emerged from the data analysis related to the interview quality. The data collected in this theme correlated both with the quality of the answers participants provided and participants' interview experience or preparation.

Fig. 13 The concept map for Theme 2: a) Question Creation

Out of three participants who were part of Phase 2, one had both college preparation for job interviews and job interview experience. Another participant was interviewed once for a volunteer position, while the third participant did not have any interview experience. This information was categorized into three subthemes: *No Interview Preparation, Interview Employment Preparation, and Interview Experience.* The data grouped into these subthemes did not correlate with the number of times a participant needed clarification on questions and used the "explain" function.

However, there was a correlation between data about the interview experience and the nature of answers participants provided, which informed the subtheme *Quality of Answers.* Most of the answers participants provided were grouped into the node *Adequate Answers.* Other nodes, such as *Long Answers, Answers Related to Different Topic,* represented the groupings of either too-long or off-topic responses. The responses that were too personal or described negative traits and negative people were regarded as outside the adequate interview response scope.

Closely connected to off-topic answers was a subtheme of *ASD-Related Influences.* The participant who previously had job coaching provided concise and on-topic replies with some explanation. The other two participants struggled with the length, points that should be included, and whether the answer should be related to professional or personal experience.

> Because one of difficulties I have is when I start opening up and start talking about something, one of my difficulties and part of its from being on the spectrum, a big part of it I have trouble stopping or knowing what information is pertinent and important and what is unnecessary. That's something I am doing my best work on. (Nicholas, Phase 2, Session 3).

Therefore, if participants could watch an instructional video before engaging with the app, the quality of the answers could improve. The instructions could provide a brief overview of the STAR Interview Technique (Doyle, 2020) and a few suggestions on the length and the topic of interview answers as per the following example:

RULES FOR EACH ANSWER:

Situation- provide the background of your story
Task- explain what was supposed to be done
Action- describe what you did
Result- report how it ended

GENERAL RULES:

Is the answer about the job?

Interview answers should always be related to work, volunteering, or school experience UNLESS you are specifically asked about personal things (i.e., things you do for fun, etc.).

What type of information to include in my answer?

Interview answers should always be related to people and situations you consider pleasant UNLESS you are specifically asked about an unpleasant situation such as a conflict with someone (i.e., to describe a situation when you did not get along with someone).

How long should be my answer?

The answers' duration is different, but the answer should have more than one sentence and not be longer than 5 minutes as a general rule.

Technology: App

Another theme that emerged from the data analysis consisted of a few subthemes that were related to accessibility, usability (UI), and user experience (UX). The subthemes related to the UI revolved around UI design principles such as easy-to-follow navigation, making call-to-action (CTA) buttons clear, and user-centered design (Ye, 2017).

At the beginning of the first session of Phase 2, the participants watched an instructional video on using an app. The instructions were reported to be clear, and they needed to watch them only one time. This confirmed the easy-to-follow navigation UI principle.

The other UI design principle that was seen in the subthemes was making CTA buttons clear. During the Codesign Development and Deployment – Phase 1, it was discovered that the bright color was more visible to participants and that there should be a color differentiation between the two buttons that were shown on the screen. Therefore, the buttons “finished” (formerly “next”) and “explain” (formerly “help”) became orange and yellow. For consistency, “yes” and “no” also became orange and yellow, respectively.

The user-centered design principles were reflected in the participants’ choice to have closed captions with the interview-questions’ audio (Phase 1). They also decided to have closed captions displayed for the duration of question-answering until they made another selection.

The Evaluation Survey that participants did after each use of the app in Phase 2 of the research consisted of questions about the font size in the closed captions, the avatar’s speech speed, and any other suggestions participants had. It influenced the iterations of the prototype, with changes in the frequency of the avatar’s blinking. It also resulted in replacing the button “help” with “explain.”

The “help” button’s erasure echoed the participants’ satisfaction. As Olivia shared:

> I hate the word “help.” I hate asking for help. It's so weird. We just don't push “help” button [referring to individuals on the autism spectrum]. Even if we want to push the “help” button—we don't!...because so many people on the spectrum will not click the button if it says “help!” (Olivia, Phase 2, Session 2)

The *UI UX Satisfaction* subtheme represented a UX design component. Additionally, subthemes *UX Session Difficulty, UX-App Enjoyment,* and *UX Value* also described aspects of UX design. The Evaluation Survey that participants completed as activity 2 of Phase 2 had a component related to the session’s ease. On a scale of 1 to 5 (with 1 being *Very Easy* and 5 *Very Difficult*) and across the four sessions, the participants rated the session “easy” (i.e., rated as 2 on the Likert-type scale) 11 times, and one participant assessed it as “average” (i.e., rated as 3 on the scale).

The same Evaluation Survey also had a part related to the pleasure participants experienced while interacting with the app. Participants had to assign a numeric value of their enjoyment on a scale of 1 to 5, with 1 being *Didn’t enjoy at all*, and 5 – *Enjoyed it a great deal*. Participants appraised sessions and stated one time that they “somewhat enjoyed it” (rated as 3 on the scale), stated eight times that they “enjoyed it very much” (rated as 4 on the scale), and stated three times that they “enjoyed it a great deal” (rated as 5 on the scale).

Therefore, participants considered the app easy to use and enjoyable. They also stated about the app that:

> It was fun! (Olivia, Phase 2, Session 2).

In the subtheme UX Value, participants reflected on the value they perceived in the app. They thought that the app was helpful to people on the autism spectrum. They saw it as a way to improve communication with individuals on the spectrum. As Nicholas declared:

> That’s why I’m really glad you’re doing this! (Nicholas, Phase 2, Session 2).

Video Performance Feedback

All the Codesign Evaluation and Revision Sessions – Phase 2 were recorded, and the link to the video content was emailed to participants. Only one participant, out of three in this phase of the research, watched the video and corrected her posture for future sessions:

> For example, after watching my first video, I stopped leaning on my hands and holding my chin because this might tell the person interviewing me that I'm bored. (Christina, Phase 2, Session 2)

Participants expressed interest in showing the video to parents and getting feedback from them. As Nicholas reported, he and his mom never had a chance to do that. However, Christina did show all the videos to her mom. It was reported that the video recordings were a great way to both see the strengths and point to the weaknesses in her daughter's job interview performance. Christina's mom described the value of the video recordings as extremely useful for feedback and job interview preparation. In conclusion, Christina's mom reported that she considered the app to be interactive and friendly.

Therefore, the video recordings seemed to help participants both as a self-correcting measure and, more importantly, as a way to obtain helpful feedback from parents or other persons constituting participants' support networks.

Questions: Scaffolding Affordances

One of the subthemes that composed Questions- Scaffolding Affordances was *Explanation Needed at "Real" Interviews.* During the Codesign Development and Deployment Phase (Phase 1), Christina talked about her interview-process experience for a volunteer position. The semistructured interviews with the participant revealed the importance of explanations of interview questions. Interview questions were not considered hard if the clarification was provided, as Christina noted:

> No, the boss was explaining to me… (Christina, Phase 1, Session 2).

The option with question clarification was considered an improved alternative:

> Yes, it was better (Christina, Phase 1, Session 2).

During Phase 1, it was discovered that the "help" function in the form of another avatar with visuals was too complex and ineffective. A different approach was taken, and the new iteration started with focus on the different structure of behavioral interview questions. The "help" function was revised. It now provided the same question in the explicit form to which the participant could answer with a short "yes" or "no." This would further lead to the related question that would ask for some examples or clarification. This sequence of questions would consist of the "main," "help," "yes," and "no" questions. In codesign sessions with participants, it was discovered that the "main" type of question was considered difficult to answer, but explicit options of the same question ("help," "yes," and "no") were deemed to be easy. The data about the questions' difficulty and the confirmation of the scaffolding method used were grouped in subtheme *Scaffolding Sequence.*

In the Codesign Evaluation and Revision Phase (Phase 2), during the first activity (Answering the Questions), the participants tested the new iteration of the prototype/app. Each participant had ten questions to answer in the course of four sessions. For the most part, participants were able to answer "main" questions. Two participants needed the "help" function three times, and one participant needed it only once. These answers informed the sub-theme *Questions-Scaffolding Answers.*

As a part of the third activity in Phase 2- Analyzing the Quality of Questions, participants were asked to assess the quality of questions they had been given earlier in the session. They were looking at all the questions in the scaffolding sequence and providing feedback. Some of the answers participants provided were grouped under the subtheme *Generic Answers- Question Quality,* and they consisted of routine "yes" replies. More specific responses were grouped into a subtheme *Specific Answers- Question Quality.* These responses were rich and vivid, and as Olivia enthusiastically affirmed:

> That's exactly the way they are going to ask it. So, that's perfect! (*Olivia, Phase 2, Session 1*).
>
> Also, another really likely question you are going to be asked. About 100 times... (*Olivia, Phase 2, Session 1*).

Participants confirmed that the scaffolding method worked well to clarify the broad behavioral questions. Additionally, if adopted by employers, the scaffolding method could provide insight into an individual's needs and demonstrate if the individual can articulate those needs. Ultimately, it could help employers better understand and learn how to communicate with individuals on the autism spectrum. As pointed out by Nicholas:

> It could help show the employer as well as... I am trying to think of how to clarify this. Part of the communication difficulties. Like, on one hand it can help the employer to see what the person's difficulties and needs are, and on the other hand it can also help show them if the person has any knowledge on how to deal with their own difficulties and needs as well. Does that make sense? (Nicholas, Phase 2, Session 1)

The data grouped in subtheme *Inadequate Teaching Practices* refers to current teaching practices for training individuals on the autism spectrum. Having attended job interview preparation courses, Olivia's experience was that if an individual on the autism spectrum did not know how to answer a question at the job interview, they were advised to ask an interviewer to:

> Just skip it! (laughing) (Olivia, Phase 2, Session 2).

The educational advice to skip the interview question demonstrates the current lack of understanding by employment trainers of individuals with ASD. It illustrates the need to improve our awareness and learn how to better communicate with individuals on the autism spectrum.

The data gathered in the Questions- Scaffolding Affordances theme has a profound impact, as it revealed that with added clarification an individual on the autism spectrum could do a job interview without skipping any questions (Olivia, Personal Communication, November 24, 2020).

Question Creation

The Question Creation theme came as a surprise as part of secondary findings. The theme development unveiled some compelling information about participants and their preferences. The highly captivating nature of the data and participants' intense feelings about these topics led to the design of the Inclusive Interview Guideline for Employers, as shown in Fig. 14.

Because the structure of our education system is designed mainly to attend to the neurotypical population, individuals on the autism spectrum often need accommodation for their differences. They are in constant need of some support that routinely attracts negative attention, and to which is attached a stigma.

This results in the internalization of a negative bias about requesting help and thus not asking for assistance even when it is needed. As Olivia illustrated:

> Even if when we want to push the "help" button—we don't! (Olivia, Phase 2, Session 2)

Additionally, the participants did not have issues with answering questions about the resolving of conflicts or the solving of complex problems. They disliked being asked to disclose moments of helplessness, panic, or mental collapse that evoked strong negative feelings about themselves, such as:

> Tell me a time about when you went blank. (Olivia, Phase 2, Session 2)

As already stated, they do not like questions that:

> . . .make me speak negatively. I don't like being negative. We just don't like talking bad about ourselves [referring to individuals on the autism spectrum]. It's taking down your own ego. (Olivia, Phase 2, Session 2)

Therefore, the Question Creation theme findings revealed that participants had hesitancy to ask for help and disliked talking negatively about themselves. These two findings, along with the previously described finding that individuals with ASD struggle with broad interview questions, constituted the few items on the Inclusive Interview Guide for Employers that employers would do well to consider when interviewing individuals on the autism spectrum. As a result of this discovery, a few options were listed in the guide that employers could implement to make the

ASD Community:
67% Unemployment Rate
Canadian Survey of Disability of 2017

Inclusive Interview Guide for Employers

When interviewing individuals on the autism spectrum, these are some of the things to consider:

- The hesitancy to ask for help
- The struggle with broad questions
- The dislike of talking negatively about themselves

If you understand this, there are some things you may do to make the interview process easier for the person on the autism spectrum:

- Offer explanations
- Offer clarification with examples
- Avoid discussing negative experiences
- Provide written form of interview questions
- Provide opportunity for asynchronous interview option

For additional readings consistent with my findings please refer to:
Autism Speaks. (2013). *Family Services Employment Tool Kit 66.*
Fraser. (2018). *Interviewing & Hiring Individuals with Autism made possible with wells Fargo foundation funds.* Retrieved from www.fraser.org

Fig. 14 Infographics: Inclusive Interview Guide for Employers

interview process easier for persons on the autism spectrum. When conducting interviews, employees could offer explanations, and clarification with examples, avoid discussing negative experiences, provide the written form of interview questions, or provide an opportunity for the person with ASD to choose an asynchronous interview option.

Communication

Some of the topics in the secondary themes related to participants' passion for art, gaming, music, and how well they were doing in these particular fields. They also included unique family influence in advocating; choosing future professions; and some personal struggles related to comorbid issues. But the topic that was discussed most of all was the prevalence of lack of understanding and communication difficulties in the social domain. As participants mostly had school experience to relate to when discussing social functioning, their examples demonstrated how these difficulties occurred or were exacerbated in the school social sphere.

The lack of understanding at school was rooted in the absence of knowledge and training. A participant described feeling not having control over school life, as the structure of school life was imposed and enforced by staff who did not know how to communicate with individuals on the autism spectrum. All the issues that come later in life derive from this lack of understanding and communication. The damage individuals on the autism spectrum experience due to lack of understanding and communication during school years have far-reaching consequences, affecting their ability to get employment, as the following comments eloquently attest:

> I didn't really have much of any control over my situation throughout school (Nicholas, Phase 2, Session 4).
>
> A lot of the issues in dealing with now, as adults on the spectrum that can affect my ability to get a job. A lot of that stemmed from how things were run in school. The fact that barely anyone on staff actually understood how people like me function. (Nicholas, Phase 2, Session 4)

> Like a lot of the issues people on the spectrum like me can have in adult life stem from everything in how things were handled in school as we were growing up. That if it's not sufficient there, it's toxic even with lasting scars and inadequacies in our ability to perform an adult life. (Nicholas, Phase 2, Session 4)

It is evident that to help improve the social quality-of-life for individuals on the autism spectrum, the most critical aspect in need of being addressed is communication. The employment status quo can only shift if we make a collective effort to increase communication with individuals on the autism spectrum.

Individuals on the autism spectrum could perform job interviews successfully if there were increased understanding and improved communication. This app can serve individuals on the autism spectrum to practice job interview questions. But, equally important, it also provides an effective method and strategies for employers to conduct inclusive interviews.

Discussion

In this participatory research, participants were involved in the codesign process of development, deployment, iterations, and testing of the prototype that generated an app with a scaffolding sequence of behavioral interview questions.

The app can provide adults with ASD the opportunity to practice the interview process in the safety of VR. Training using the app may help individuals on the autism spectrum to build confidence in the social skills necessary for successful job-interview performance. The video recordings could help users assess their performance and gain feedback. They can use the VSM aspect and apply it as a self-correcting measure for additional elements of the interview process such as posture, eye contact, etc. The design intention, supported by the research findings, is represented with the tetrahedron artifact 1, shown in Fig. 15.

The unique method of the scaffolding sequence is designed with human uniqueness and variability in mind. The scaffolding provides an opportunity for individuals with diverse verbal and cognitive abilities to use an app successfully. It delivers a specific version of the broad behavioral questions and prompts users to provide more information about themselves, as shown in Fig. 16.

The study revealed additional ways to better communicate with individuals on the autism spectrum. The findings resulted in the development of the Inclusive Interview Guide for Employers.

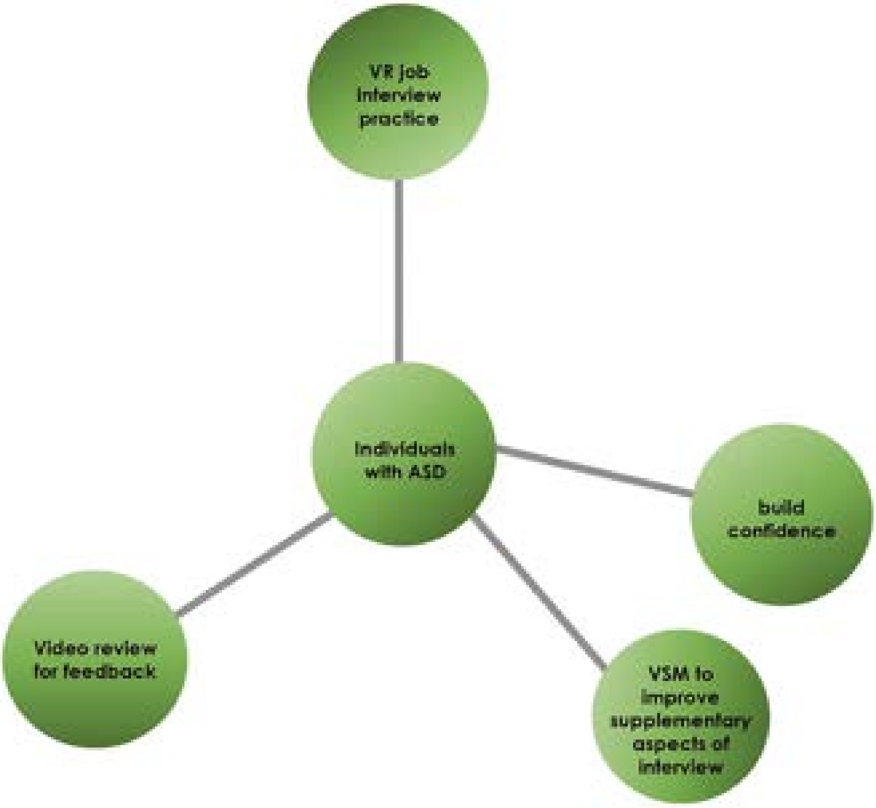


Fig. 15 Tetrahedron Artifact 1: VR/VSM for individuals on the autism spectrum

Fig. 16 Scaffolding sequence of behavioral interview questions

Additionally, the app allows employers to input their questions, customize the interview process, and use it as an asynchronous interview alternative. It can also enable employment agencies to prepare clients for future jobs. The provision of another way to do job interviews can contribute to a more inclusive interview process. The customizing option ensures flexibility that other VR studies do not demonstrate. This alternative enables the use of the app to create interview questions for specific jobs as well. Nicholas expressed an interest in such a possibility:

> And if it [referring to an app] also includes examples of kinds of questions that someone might be asked while pursuing a particular position, I think that would also be helpful. (Nicholas, Phase 2, Session 1)

The video recordings proved effective not only as VSM but also as feedback. The new iteration allows for the provision of text transcripts sent to the user's email. These features can help employment-support agencies to provide feedback to their clients on the autism spectrum. Currently, employment-support agencies and programs provide training on creating resumes and a general overview of interview questions. The employment-support programs could use an app to help their clients get ready for job interviews and to assess their performances.

A previous study has revealed that VR job-interview training is beneficial for neurotypical individuals who have been unemployed for more than 1 year (Aysina et al., 2016). The anecdotal survey findings from the Inclusive Spectrum Exhibition confirm the interest of neurotypical individuals in using an app (Inclusive Spectrums: VR/VM Job Interview Training for Individuals with ASD, 2020*)*.

The findings of this research and the app can affect all of the parties involved in the employment system, as represented with the tetrahedron artifact 2, shown in Fig. 17. It can result in a more inclusive employment structure.

The further iteration of the app could include video recording with file size acceptable for mobile storage. It may also involve an instructional video at the beginning of the app to ensure concise and on-topic answers. Future studies could test the feasibility of the instructional video and include neurotypical participants.

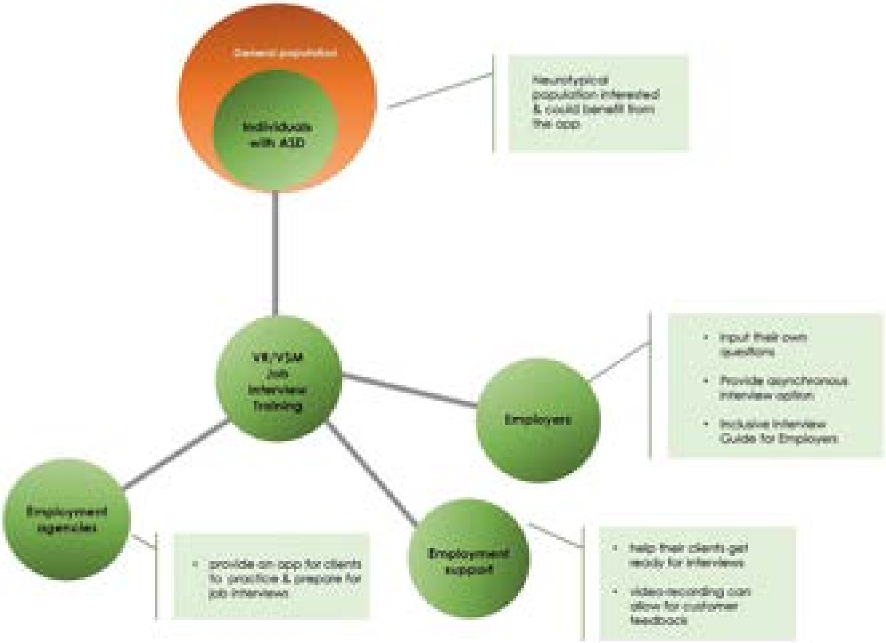


Fig. 17 Tetrahedron artifact 2: inclusive employment structure

Conclusion

This research represents a fulfillment of a longing to contribute to the inclusion of individuals on the autism spectrum. The world of autism is a realm where a constant chase of “normalcy” starts from the first signs of autism a toddler shows and never ends.

Individuals on the autism spectrum are expected to perform self-erasure daily to be part of our neurotypical world. If we made an effort to learn how to communicate with these atypical individuals, we would discover a dimension of unprecedented honesty, dependability, commitment, focus, precision, and diligence.

The possibility of inclusive interviews would be a benefit to all of us. We could realize a wholesome society where everyone, including individuals on the autism spectrum, would have an equal employment opportunity regardless of their unique expression.

Appendix A: Additional Material

Title: Cocreating Inclusive Interviews

Description: VR technologies for job interview training of individuals on the autism spectrum and strategies for employers

Date: April 24, 2021
Accessible Version – YouTube Video Link: https://youtu.be/ZlT1zDpjvL8

Appendix B: Scaffolding Sequence of Questions

Question 1: **Tell me about yourself**.

- If a participant selects “help”: **Have you worked or volunteered anywhere before?**
  - If a participant selects “yes”: **Did you use a computer to send emails?**
  - If a participant selects “no”: **Did you use a computer at school to send emails?**

Question 2: **Tell me about the time you worked in a team**.

- If a participant selects “help”: **Did you ever work in a team at school, volunteering job, or a real job?**
  - If a participant selects “yes”: **How did you like working in a team?**
  - If a participant selects “no”: **Do you like to work with people?**

Question 3: **What are your greatest strengths?**

- If a participant selects “help”: **Are there personal qualities that make you good at school, a volunteering job, or a real job?**
  - If a participant selects “yes”: **What are those qualities?**
  - If a participant selects “no”: **What are the things you want to become better at?**

Question 4: **What is your greatest accomplishment?**

- If a participant selects “help”: **Have you ever won an award, or did someone praise you?**
  - If a participant selects “yes”: **What were you awarded or praised for?**
  - If a participant selects “no”: **What are some of the things that you do really well?**

Question 5: **What are you passionate about?**

- If a participant selects “help”: **Do you have things that you do for fun?**
  - If a participant selects “yes”: **What are the things that you like to do for fun?**
  - If a participant selects “no”: **Do you do things at home for fun?**

Question 6: **Tell me about the situation where you had to solve a difficult problem and how you did it**.

- If a participant selects "help": **Have you ever had a difficult situation at school, a volunteering job, or a real job?**
  - If a participant selects "yes": **What was the difficult situation, and how did you problem-solve it?**
  - If a participant selects "no": **What do you do at home when you can't do something by yourself?**

Question 7: **Tell me about the time you went "above and beyond."**

- If a participant selects "help": **Did you do something extra for your school project, a volunteering job, or a real job that wasn't asked of you?**
  - If a participant selects "yes": **What was it that you did extra that wasn't asked of you?**
  - If a participant selects "no": **Do you help at home with chores without being asked?**

Question 8: **Describe a time you went out of your way to help somebody.**

- If a participant selects "help": **Did you ever help someone at school, a volunteering job, or a real job?**
  - If a participant selects "yes": **Who was it that you helped, and how did you help?**
  - If a participant selects "no": **Do you help others at your home?**

Question 9: **Tell me about the time you had to adapt to change over which you had no control**.

- If a participant selects "help": **Was there ever a change of routines at your school, volunteering job, or a real job?**
  - If a participant selects "yes": **What was a change, and what did you do about it?**
  - If a participant selects "no": **Have you ever had any sudden changes in your routines at home?**

Question 10: **Describe a situation where you didn't get along with someone**.

- If a participant selects "help": **Was there ever a person at your school, a volunteering job, or a real job that you didn't get along with?**
  - If a participant selects "yes": **How did you handle it when you didn't get along with the person?**
  - If a participant selects "no": **Do you always get along with others in your house?**

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Inclusion of Persons with Disabilities by Design: From Product Centered to Justice and Person Centered Inclusive Co-design

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James Rwampigi Aniyamuzaala

Contents

Abstract

Persons with disabilities and their needs were excluded by design according to the article 2 of the Convention on the Rights of Persons with Disabilities. The review of the literature and secondary data revealed the three inclusive design school of thoughts and practices, and these included the following: The Canadian, the United Kingdom (UK), and the Technology Industry's Inclusive Design school of thoughts and practices. The qualitative critical analysis of the three inclusive design school of thoughts resulted into the Justice and Person Centered Inclusive

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Co-Design (JPCICD) as the fourth inclusive deign school of thought and practice. The JPCICD expands on the Canadian inclusive design school of thought and practice to comprehensively cover justice, equity, and human diversity dimensions of design. The JPCICD shifted the focus of inclusive design from product and market system to person's social, political, economic, cultural, and technological justice or total justice. It also considers the equity principle in its definition. The JPCICD was developed based on the foundation of the human rights and justice principles such as equity and equality human diversity, freedom of choice, and others. JPCICD focuses on equitable distribution of resources and power to the diverse excluded persons with disabilities by design.

Keywords

Inclusive design · Human diversity · Persons with disabilities · Justice

Introduction

The chapter examined the secondary data related to inclusive design practices and school of thoughts and the challenge of exclusion of persons with disabilities and their needs by design. The qualitative research study analyzed how the different inclusive design school of thoughts facilitated equity, justice, and freedom of choice of the diverse persons with disabilities in the design processes and practices. The chapter was based on the review of the research work of Prof. Jutta Treviranus and Clarkson, Coleman, Hosking, Waller, and colleagues on Inclusive design methods and practices. The chapter complimented and expanded on the inclusive design research work developed by Inclusive Design Research Center, Canada. The review of the research work on inclusive design methods, processes, and practices resulted into the development of the Justice and Person-Centered Inclusive Co-Design (JPCICD) school of thought and practice. The JPCICD centers the person at the center of design and considers justice, equity, human diversity, and freedom of choice in the design processes and practices that address the exclusion of the diverse persons including persons with disabilities. The development of the JPCICD Inclusive Design school of thought and its comparison with other design practices were examined in detail as follows.

The Exclusion of Persons with Disabilities by Design

Approximately One billion people globally were diverse persons with mild to moderate to severe disabilities (World Health Organisation and World Bank, 2011). Persons with disabilities were composed of the different groups of persons such as persons with deafblindness, persons with intellectual disabilities, persons with psychosocial disabilities, persons with hearing, visual, and communication disabilities, and persons with physical disabilities and others (World Health Organisation and World Bank, 2011). Research studies (Olkin et al., 2019) revealed that a significant number of persons have invisible disabilities, and their needs cannot be predicted without personalized assessment. The United Nations Convention on Rights of Persons with Disabilities noted that designs excluded persons with disabilities and their needs. The CRPD prohibited exclusion of assistive technology (AT) needs of the specific persons with disabilities such as persons with deafblindness by Universal design (The United Nations, 2006).

The Ireland’s 2005 Disability Act confirmed that Universal design does not consider the AT needs of some of the diverse persons with disabilities. It stated that, “Universal design (a) means the design and composition of an environment so that it may be accessed, understood and used; (i) to greatest practicable extent, (ii) in the most independent and natural manner possible, (iii) in the widest possible range of situations, and (iv) without the need for adaptation, modification, assistive devices or specialised solutions by persons of any age or size or having any particular physical, sensory, mental health or intellectual ability or disability,” (Republic of Ireland, 2005). The universal design implied that persons with disabilities such as persons with deafblindness in need of adaptations, modifications, and assistive technology products were excluded by design because the one-size-fits-all approach and does not address their specific personal needs. Based on the above background, this chapter examines how the inclusive design processes and practices addressed the exclusion of persons with disabilities by design.

Methodology

The methodology was composed of the review of the secondary data on inclusive design methods, processes, and practices developed by Prof. Jutta Treviranus and Inclusive Design Research Center, Canada (IDRC). The Inclusive design methods and practices in the UK were also examined in this chapter. The data was analyzed based on the research proposition that stated that all the design methods, processes, and practices considered justice, equity, freedom of choice, and human diversity, and address the needs of each of the diverse persons with disabilities (Yin, 2018). The main source of the secondary data reviewed in this chapter was the research study by Prof. Jutta Treviranus of 2018 on the three dimensions of inclusive design: A design framework for a digitally transformed and complexly connected society, PhD thesis, University College Dublin, http://openresearch.ocadu.ca/id/eprint/2745/ (Treviranus, 2018). The other sources of data were: the 2007 Inclusive Design Toolkit, Cambridge University, http://www.inclusivedesigntoolkit.com/ by Clarkson, Coleman, Hosking, Waller, and colleagues (2007). The secondary data was examined in detail as follows.

Inclusive Design and Persons with Disabilities

Some of the design methods and practices excludes some of persons with disabilities and their needs, as confirmed by the Convention on Rights of Persons with Disabilities and the 2005 Ireland´s Disability Act (The United Nations, 2006; Republic of Ireland, 2005). Inclusive design emerged as a design method and practice to address the exclusion of diverse persons including diverse persons with disabilities. It recognises persons with disabilities as one the human diversity dimensions. Inclusive design, through the one size fits one and expand to many approach and practices, centers each of the diverse person with disabilities at the center of the design processes. This implied that inclusive design recognises the human diversity within the different categories of persons with disabilities (Treviranus, 2018).

The Inclusive Design School of Thoughts and Practices

Jutta Treviranus (2018; p79) acknowledged the development of the UK and Canadian inclusive design school of thoughts and practices. The UK inclusive design school of thought emerged from engineering, higher education, industrial design, and business groups to address the product design. The UK inclusive design centered product inclusivity and market expansion to persons with money at the margins of society as a result of the design. The Canadian inclusive design school of thought and practice emerged from a community tackling computer access and digital inclusion through co-design and co-development processes and practices. The Canadian inclusive design was established by a community of practice led by IT developers and professionals with the support of community users of products, services, environments, and facilities. The two inclusive design schools of thoughts and practices were analyzed in detail as follows.

The UK Inclusive Design School of Thought and Practices

Jutta Treviranus (2018; 79) noted that the UK inclusive design school of thought and practices focused on physical product design and not justice, equity and equality, freedom of choice, and other human rights principles. The inclusive design toolkit was developed by Clarkson, Coleman, Hosking, Waller, and colleagues (2007) at the Engineering Design Centre of the University of Cambridge. Prof. Jutta Treviranus noted that the UK inclusive design school of thought was developed as a business compromise to the perceived unrealistic aspirations of universal design. The UK inclusive design school of thoughts and practices focused on the development of the commercial solutions and not addressing social, economic, political, cultural, and technological justice demands of persons with disabilities and other diverse persons excluded in the design practices and processes (Treviranus, 2018).

The Inclusive Design Toolkit site of the University of Cambridge differentiated universal design and inclusive design as follows: “In contrast, inclusive design originated with product design, and focuses on choosing an appropriate target market for a particular design and making informed decisions to maximise the ‘Product performance indicators’ for that target market. While Inclusive design intends to extend the reach of mainstream products, it acknowledges the commercial constraints associated with satisfying the needs of the target market” (Clarkson et al., 2007). The UK inclusive design school of thought and practice focused on the expansion of the market of the products by designing the family of the same products that meets the different targeted markets including persons with disabilities’ markets.

Inclusive design practices in UK was referred to as the product-centered inclusive design because it prioritized products at the center of design and not persons, including persons with disabilities (Treviranus, 2018).

The British Standards Institute's Inclusive Design

Clarkson, Coleman, Hosking, Waller, and colleagues (2007) noted that the British Standards Institute defined inclusive design as follows: "The design of mainstream products and/or services that are accessible to, and usable by, as many people as reasonably possible ... without the need for special adaptation or specialised design." This definition of inclusive design promoted the narrative that universal design was the same as inclusive design since both considered accessible mainstream products and environments usable by many to the greatest extent possible without the need for adaptation. It also promotes the narrative that for All or universal design and accessibility (Cremers et al., 2013).

However, the Inclusive Design toolkit clarified that inclusive design was not the same as universal design or Design for All through the acknowledgment that one size does not fit all. The Inclusive Design toolkit noted that inclusive design does not suggest that it was always possible or appropriate to design one product to address the needs of the entire diverse population. The inclusive design toolkit confirmed that inclusive design was a valid and appropriate design response to human diversity within the population of people excluded through the following: Developing a family of products and derivatives to provide the best possible coverage of the population. Ensuring that each individual product has clear and distinct target users. Reducing the level of ability required to use each product, in order to improve the user experience for a broad range of customers, in a variety of situations. The British Standards Institute's inclusive design practices considered persons with disabilities to have the same needs that were addressed through a one-size-fits-all approach and design. Design focused on product development and not social, economic, cultural, and political justice aspects related to consumer rights and exclusion of diverse persons from use or benefiting from products, services, systems, environments, and others (Clarkson et al., 2007).

The UK User-Sensitive Inclusive Design

Jutta Treviranus (2018; p83) noted the development of User Sensitive Inclusive Design by Newell and colleagues at University of Dundee computer science department. Newell and Gregor (2011) used user-centered and user-sensitive inclusive design as a response to difficulties related to Universal design and user-centered design. The specific needs of older persons and persons with disabilities were not addressed by a universal user-centered design for all. The attempts to address their needs within the framework of universal design for all resulted in add-on accessible alternative solutions that were not equivalent or interoperable with solutions designed for all. User sensitive inclusive Design was developed based on the notion that all persons were users.

Jutta Treviranus (2018; p83) further noted that the use of sensitive by Newell and colleagues encompassed a more empathic relationship with the users. It was a response to designs that treated persons with disabilities and older persons as test subjects for usability experiments. This further proves that the user-sensitive inclusive design did not share power and resources with persons with disabilities and older persons often excluded because of both less power and resources. It considered them as objects of experiments, and this advanced the Charles Darwin narrative of survival of the strongest and the individual liberal capitalism that treats all people as market commodities. It did not recognize persons with disabilities as rights holders with freedom of choice.

Jutta Treviranus (2018) revealed that the use of the UK inclusive design principles to design digital systems, networks, software, and services came later in the UK and was influenced by researchers in computer science at the University of Dundee and the Helen Hamlyn Centre for Design at the Royal College of Art in London co-founded by Roger Coleman and Jeremy Myerson. The UK inclusive design practices and methods aimed at expanding the beneficial impact of products and built information and communication environments to persons with disabilities and older persons at the margins with similar needs. Inclusive Design practices and methods used in UK do not consider justice, equity, and freedom of choice dimensions of design. The product was at the center of design and not persons with disabilities.

The Canadian Inclusive Design School of Thought

The Inclusive Design Research Center (IDRC) at the Ontario College of Art and Design (IDRC-OCAD) University, Canada (Inclusive Design Research Center, 2018), defined inclusive design as "design that considers the full range of human diversity with respect to ability, language, culture, gender, age and other forms of human difference." The three dimensions of the Canadian inclusive design school of thought and practice included the following: recognition of diversity and exclusion; inclusive processes and tools; and broader beneficial impact. Jutta Treviranus (2018; p79) noted that the Canadian inclusive design school of thought emerged from the global community of practice that tackled computer access and digital inclusion, and focused on personal computers, digital documents, software applications, interfaces, Web systems, and all things computer-mediated and networked.

The Canadian Inclusive design was rooted in the digital systems and networks that provided flexible personalized design and opportunities for a wide range of users. It differed from the UK Inclusive design school of thought that focused on addressing the business challenges related to Universal design. Jutta Treviranus (2018; p84–p85) confirmed that the Canadian Inclusive design shared the social justice values for the disability movements. The social justice values for the Disability Rights Movement were promoted and protected by the Convention on Rights of Persons with Disabilities (CRPD) as an international human rights law ratified by member states.

The CRPD article 3 principles included the following principles: the full and effective participation and inclusion in society, equality and equity, non-discrimination, respect of human diversity, respect of freedom of choice and others as captured by article 3 of the UN Convention on Rights of Persons with Disabilities (United Nations, 2006). The development and practice of Inclusive design within the social justice and human rights contexts resulted into the Social Justice Inclusive design or Justice and Person Centered Inclusive Design.

The Technology Industry’s Inclusive Design School of Thought and Practices

The Microsoft developed Inclusive design guide to ensure that their software products and human resource environments were inclusive and accessible to all diverse persons including persons with disabilities. The Microsoft Inclusive design practice was considered as the implementation of the Canadian inclusive design in the tech industry context with the aim of expanding the market for tech products and services. The IDRC Canada contributed to the development of the Microsoft Inclusive design practices and guide as a means of building inclusive and socially responsible businesses and industries. Inclusive design was used as a tool to widen the accessibility of digital products to be usable by as many people as possible, thus expanding the market. The other tech companies that used inclusive design were Apple (2021) and Adobe methods and practices to ensure that their products, such as computers and software, were accessible and usable by as many people as possible at the edges of the society. This section of the research paper critically analyzes the Canadian inclusive design school of thought and practices within the justice, social justice, and human rights contexts (Microsoft, 2018).

The Justice or Person-Centered Inclusive Co-design School of Thought

The UK Inclusive Design School of thoughts and technology industry applied and practiced inclusive design within the market system. The two schools of thoughts focused on the expansion of the market for their products by reaching out to new customers who could not use their existing products and services. The Canadian Inclusive design school of thought and practice was developed by academicians, open-source software developers, and ICT developers to reduce the exclusion of the diverse persons including persons with disabilities. The Canadian inclusive design school of thought did not prioritize equity, justice, freedom of choice, and human rights by design. This section examines the Canadian inclusive design school of thought based on justice and human rights principles and practices. The outcome was the justice or person-centered inclusive co-design (JPCICD) school of thought. The JPCICD transforms the inclusive design into a justice and human rights tool and process for achieving full and effective participation and inclusion in political, economic, social, cultural, and technological activities of society and adequate well-being of the person. The JPCICD does not only center the diverse persons with disabilities at the center of design, but it also prioritizes justice, equity, and freedom of choice of the person at the center of the design (United Nations, 2006; Treviranus, 2018).

The Justification for the Justice or Person-Centered Inclusive Co-design

The section of the research paper defines justice or person-centered inclusive co-design (JPCICD) as a design that considers justice, equity, human diversity, freedom of choice, and other human rights principles in the design of environments, products and services, facilities, and others to realize full participation in all life environments and well-being of each of the diverse persons. The JPCICD expands the Canadian definition of inclusive design by IDRC OCAD University to include justice and equity and freedom of choice. It applied the human rights and justice lens on the Canadian inclusive design school of thought and practice. The justification of JPCICD was based on several factors that have been examined as follows.

The Exclusion of Assistive Technology (AT) Needs of Persons with Disabilities

The Convention on Rights of Persons with Disabilities through article 2 stated that "Universal design shall not exclude the use of the Assistive technologies (AT) used by persons with specific disabilities" (The United Nations, 2006). The definition of universal design in Ireland´s 2005 Disability Act excludes AT devices and prohibits adaptations of environments and products to meet the specific needs of persons with disabilities whose needs are not addressed by one-size-fits-all products and services (Republic of Ireland, 2005). The diverse persons with deafblindness have specific needs that require a person-centered inclusive co-design with persons with deafblindness and their caretakers to find the appropriate accessibility accommodations including AT products and services. Research studies revealed that persons with deafblindness were among the most affected group of persons with disabilities by environmental barriers, poverty, and other inequalities. Research studies also show data desert for persons with deafblindness, and they were invisible in the data collected based on the set of questions of the Washington Group on Disability Statistics (World Federation of the Deafblind, 2018; Washington Group on Disability Statistics, 2022).

The Nordic research center for rehabilitation technology (2007; p4–p16) further confirmed that universal design could not be applied to design of AT solutions for the diverse persons with different AT needs and personal characteristics. This confirmed that the JPCIC was the appropriate design practice that adapts the AT solutions to the AT needs of diverse persons with disabilities and expands to many with less difficulties. Speech to Text for persons with hearing loss and ear assistive technology (HEAT) solutions such as captions were used by both persons with and without hearing loss. The AT solutions were based on freedom of choice and rights of the person in need in Norway. The state shared the resources and power with the person at the center of design of AT solutions and service delivery systems.

The JPCICD as a Social Justice Tool for Distribution of Power and Resource

The one-size-fits-all design implied that designed products were supposed to be used by all without the need for adaption and inclusive co-design with diverse persons including persons with disabilities. Persons with disabilities were considered among the most affected population by poverty. They have low purchasing power for market goods and services. The attitudinal barriers facilitate an environment that considers persons with disabilities as objects without power to influence decision-marking and markets. Sometimes persons with disabilities were consulted in design as passive participants without power to influence the design processes and practices. The JPCICD and interactive practices means a process that shares the decision-making power and resources with the diverse person at the center of the design to facilitate the full participation, inclusion, and well-being of that person, especially a person with disabilities (Olkin et al., 2019; Treviranus, 2018).

The freedom of choice and influence of the person at the center of the design in the decision-making of the design processes was a parameter used for measuring the equal power sharing between the person and design team or designer. The design tools and processes should be inclusive and accessible to allow the inclusive participation of the person in the design processes. The achievement of the full participation in the different life environments and adequate well-being of the person was considered as a measure of the share of the resources between the person at the center of the design and the design teams. The outcome of the inclusive design should be based on the freedom of choice of the person at the center of the design and be inclusive, accessible, and usable by a person at the center of the design without economic, political, cultural, social, and technological barriers and others (United Nations, 2006; Treviranus, 2018).

The Dynamic Personal Features and Environment and Human Diversity

Newell and Gregor (2011) confirmed that the personal features and environment were dynamic and the design for users especially for older persons required consideration of dynamic human diversity and environment. Jutta Treviranus (2018; p13–p64) argued that the human interactions within the changing environment were complex and these were part of the complex adaptative system. Jutta confirmed that the closed classification and categorization systems exclude persons without similar characteristics based on to form classes and categories. Jutta advocates for open education resources and open software, and these represented the open classification and categorization systems that adapt to human diversity, dynamic personal features, and environment. Education was an outcome of the categorization system, and software were outcome of the product classification system. The JPCICD was developed based on the human diversity, personal features, and environment to respond to the unique needs such as needs of persons with varying degrees of functional difficulties, environmental barriers, participation restrictions, and new needs that emerge from the society's complex adaptative system interactions. It is the iterative path of expanding the beneficial impact to diverse persons.

From the Product to the Justice or Person-Centered Inclusive Co-design (JPCICD)

This discourse shifts the focus from products and services centered inclusive design to person-centered inclusive design. This research paper thesis integrated the inclusive design with the human rights-based approach and human rights principles under article 3 of the UN Convention on Rights of Persons with Disabilities to establish the social justice inclusive design or person-centered inclusive design. The CRPD through article 9 on accessibility confirmed that the design of inaccessible information, communication, technology, and built environments that excluded persons with disabilities from usability of services, goods, facilities, environments, and others. The CRPD article 9 also confirmed that design for accessible services and goods, environments, and others for all diverse persons was a social justice and human rights issue (United Nations, 2006).

The Design for All and JPCICD

Jutta Treviranus (2018) noted that the Design for All philosophy emerged from Europe was formalized in the European Institute for Design as a standard and the 2004 Disability Stockholm Declaration (European Standard Agency, 2019). Jutta argued that the Design for All was applied across all areas of design and recognized three approaches to providing access to information and communication technology (ICT). ICT that can be accessed by nearly all users without modification. ICT that can be modified to provide access to different needs and standard technologies that interoperate with assistive technology. Jutta argued that the Stockholm declaration aligned Design for All to Inclusive design by stating that, “The practice of Design For All makes conscious use of the analysis of Human needs and aspirations and requires the involvement of end users at every stage in the design process.” The involvement of users in every stage of design was the first step towards sharing power and resources with the users to influence a design system that develops person-centered inclusively designed environments, services, products, and facilities.

In addition, both Design for All and Inclusive design recognized user diversity and provided for user diversity through one size fits each user diversity. Design for All considered design for ICT used by many without the need for adaptation. It also recognized design of ICTs that were modified and adapted to meet the different needs of diverse persons. Design for All considered design for standard ICTs that interoperate with assistive technologies used by diverse users. The assistive technology solutions were a personal solution outcome of a person-centered inclusive design practice as confirmed by the UNCRPD that stated that “Universal design shall not exclude Assistive Technology” (The United Nations, 2006). The Design for All did not recognize resources and power as part of the design processes that exclude persons.

The Universal Design for Learning and JPCICD

Jutta Treviranus (2018) noted that David Rose and Ann Meyers as founders of CAST in Boston published Teaching Every Student in the Digital Age: Universal Design for Learning (Rose and Meyer, 2002). The publication noted that UDL has the following three principles below: provide multiple means of engagement, provide multiple means of representation, and provide multiple means of action and expression. Jutta Treviranus argued that the User-centered design shifted to put the user at the center of the design and shifts the learner to the center of education. The principles were aligned with inclusive design approach of one-size-fits-one approach to user diversity or different needs of the diverse persons. The universal design for learning principles also reflected an effort to shift power to the user through multiple means of engagement, the provision of multiple means of representation, and multiple means of action and expression. However, these cannot be achieved without the adaptations, modifications of the environments, and the use of AT to support participation and representation of the diverse persons with disabilities such as persons with deafblindness. Universal design for learning was also silent on justice and the shifting of resources to the user, which are key factors in determining an equitable distribution of power and resources.

Jutta Treviranus (2018) revealed the collaboration of CAST since 1990s on education learning projects. The divergence in approaches used by the Inclusive Design Research Center (IDRC), Canada, and CAST were as follows: the IDRC focused on open education resources and the application of educational technology to enable the personalization of learning. This was done through projects such as the inclusive learning exchange, flexible learning for open education, ATutor, and other projects that promoted personalized one-size-fits-one delivery of learning experiences through the inclusive system. This reflected share of resources to facilitate participation and inclusion of learners in education programs. However, the power shift to learners with disabilities to make decision on education programs of their choice was not clearly defined and measured. The JPCICD shifts the power and resources to the person at the center of the design through equitable sharing of resources and power and based on the freedom of choice of the person at the center of the design.

The CAST worked extensively with educational textbook publishers and served learner diversity through curriculum approaches that provided students with diverse curriculum options for a given learning goal. Jutta argued that the CAST approach was linked to the universal design of a built environment that anticipated the range of visitor needs in advance. The students' needs were anticipated in advance rather than adjusting the curriculum when the students arrive. Jutta further noted that the two approaches were complimentary in the joint project between CAST and IDRC Canada called Center on Inclusive Software for Learning (CISL) that focused on open education resources. The CAST approach was also not clear on the distribution of power and resource between the learners and the hierarchical education system administrators. It did not define the freedom of choice of the learner that is key in democratization of the education system and building inclusive education systems (CAST, 2018).

Jutta Treviranus (2018, p84) noted the development of differentiated learning by Morgan (2014) as a teaching philosophy and approach that was based on the design of the curriculum on iterative assessments that guided the modifications of the instructional material and teaching approach to diverse students. Jutta argued that inclusive system enables adaptation of curriculum and personalization of learning to address the different learning needs of the diverse learners. Inclusive systems were grounded on the computer digital system, open software, and user-centered design. The inclusive system also shares the resources and power with the learners and persons with less power and resources. This shows that adaptations, modifications, and use of AT were necessities for facilitating inclusive education systems. This was referred to as inclusive learning by design (ILD) or inclusive design for learning. These were part of inclusive education by design (IED).

The Universal Design and JPCICD

The universal design was defined as design of products, services, environments, and others to be used by as many people as possible without the need for adaption. The universal design promoted a practice of one size fits all the needs of the diverse persons. The IDRC Canada (2018) noted that universal design and inclusive design both facilitated inclusion and accessibility of services, products, environments, and others by all diverse persons. However, the two design methods differed in how they addressed the user diversity needs and how they originated from the different fields of studies. The universal design emerged from the engineering or from group of people advocating for accessible built environment in the USA. These were concerned with the inaccessible built environment for persons with disabilities. It was developed to address the built environment inaccessibility later expanded to other life environments like ICT and learning. The inclusive design emerged from the computer science, Web, and open software communities, and it worked with flexible and personalized digital systems. The person-centered inclusive design was driven by the social justice movement that call for equitable distribution of resources, power, inclusive participation, and accessibility of services, products, environments, and facilities (Treviranus, 2018; Inclusive Design Research Center, 2018).

The Universal design was based on a one-size-fits-all approach, as there was no need to adapt the environments, services, products, and others to the needs of the person. Universal design focused on addressing the needs of persons with disabilities as a priority. Inclusive design was based on an inclusive system that addressed the diverse needs through a one-size-fits-one approach and expand to many. It adapted the environments, products, facilities, and others to the needs of the diverse users. Inclusive design does not only focus on the diverse persons with disabilities but also prioritizes all other diverse groups such as older persons, children, women, and others. The universal design did not recognize equitable distribution of resources and power between the person and designers. The JPCICD considers the distribution of power and resources (The United Nations, 2006; Inclusive Design Research Center, 2018).

The JPCID Wider Beneficial Impact

Persons without difficulties or disabilities find it much easier to use the products, services, and environments designed to be used by persons with varying difficulties or disabilities. The captions or speech-to-text services were designed to be used persons with hearing difficulties but they also benefited persons with language difficulties and learning difficulties. The telephone was initially designed as a solution for a person with hearing loss and now it is used by most of persons as a communication solution. The easy to read and understand texts benefits persons with intellectual difficulties and persons with low levels of education. The late Olof Palme, former prime minister of Sweden, once said that, “The quality of life of society can also be measured by how such society treats it’s most vulnerable citizens. If the most vulnerable are well off, then those who do not have vulnerabilities are far better off’ (Treviranus, 2018).

JPCIC-Related Practices, Processes, and Tools

This section of the research paper examined the JPCICD processes, tools, and related practices. The inclusive design processes and tools, individual rehabilitation and vocational rehabilitation plans, individual education plan, and international legal framework for JPCICD were examined in detail below.

The Inclusive Processes, Tools, and Practices

The second dimension of the Canadian inclusive design was inclusive processes, tools, and practices, according to Jutta Treviranus (2018). The sharing of resources and power requires inclusive processes, tools, and practices that makes the usability of the design systems, environments, services, products, facilities, and others adapted to the personal needs. The inclusive processes, tools, and practices are part of the reparation interventions and practices to distribute power and resources equitably and responsibly. The inclusive processes, tools, and practices address discrimination, apartheid, racism, violence, and other forms of exclusion in the design of economic, political, technological, cultural, and social systems of power and resources. JPCICD centers persons with disabilities at the center of the design through the inclusive processes, tools, and practices.

The JPCICD Normative and International Legal Framework

The CRPD article 2 (The United Nations, 2006) stated that, “Universal Design shall not exclude the use of assistive technology.” This statement in the UNCRPD forms the international legal framework for the inclusive design or person-centered inclusive design. Assistive technology is an outcome of a person-centered inclusive design. The design process adapts the services, environments, facilities, and products, including assistive technology products and services, to the person's needs or characteristics and environmental requirements. The UNCRPD's reference to assistive technology is not to be excluded by universal design. Treviranus (2018) defined universal design as a design that responds to as many people as possible without adaptation and confirmed the PCICD in international human rights law as a design that responds to the needs of diverse persons, including persons with disabilities.

The JPCICD-Related Practices

This section of the research paper examined the different practices that relate to the JPCICD. Individual rehabilitation and vocation rehabilitation plan and individual education plan practices in Finland and the USA, respectively, were identified as the practices that relate to the JPCICD. These were examined in detail below.

The Individual Rehabilitation and Vocational Rehabilitation Plans

The individual rehabilitation and vocational rehabilitation plans in Finland were based on assessment of the person's rehabilitation needs and selection of the rehabilitation and vocational rehabilitation solutions based on freedom of choice of the person. The state shared the resources and power in the design of the personal vocational rehabilitation plan and the implementation of the vocational rehabilitation plan according to the Nordic center for rehabilitation technology (Nordic Center for Rehabilitation Technology, 2007).

The Individual Education Plan

The development of the individual education plan was a fulfillment of the 2004 Individuals with Disabilities Education Improvement Act. The development of the plan centers the learner's needs and participation at the center of the design of the individual education plan. The needs and the solutions or responses to the needs were based on freedom of choice of the learner. The state covers some of the costs of the interventions of the individual education plan. However, the IEP does not define the freedom of choice and equitable distribution of resources and power between the learner and school administration (US, 2004).

Conclusion

The Justice or person-centered inclusive co design practice emerges from the Canadian inclusive design school of thought and social justice movement. It does not only center the person's needs but also centers their participation in the design of services, products, environments, facilities, and system to respond to the personal needs. However, it also shared the power and resources with persons at the margin of society to facilitate full and effective participation and inclusion of diverse persons in all life environments. It was based on social justice values of an equitable share of resources and power, Non Discrimination, freedom of choice, gender equality, and full and effective participation and inclusion in society. The JPCICD was developed based on the open classification and categorization system that expand the beneficial impact to persons with unique different needs at the margins of the society. Persons without disabilities or difficulties find it much easier to use the public services, products, and environments designed with and by persons with varying degrees of difficulties or disabilities. The ramp benefits wheelchair users with permanent, temporary, and situational mobility needs, pregnant women, mothers with baby strollers, older persons, the emergency evacuation response team, and others.

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Compassion as a Tool to Enhance Communication Between Nurses and Children in the Oncology Pediatric Ward

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Contents

Abstract

This research project (RP) presents a communication tool designed through an experience-based co-design (EBCD) method that aims to increase empathy and establish an emotional connection between pediatric oncology patients and the nurses that care for them. We ask: What value can the personal experiences

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of participants bring to the design process of a tool that is intended for their use? We explore this question by first conducting a series of interviews with four pediatric oncology patients and nine nurses of the pediatric oncology ward, focused on identifying and understanding the emotions they experience during the different procedures that take place during the patients' stay in the hospital. The data collected during these interviews were used to create emotional maps that directly informed the design of a mobile application, which allows users to collaborate by recording customized audio stating their feelings and agreements between both parties, which they can later listen to during painful and emotionally tolling procedures. Participants then tested the prototype in a series of workshops where their feedback was collected and integrated into a second and final prototype. Our results show that (1) pediatric oncology patients and the nurses that care for them are open to and enthusiastic about using a tool to work together and empathize with one another, (2) an EBCD method is helpful to understand abstract emotional conditions, and (3) tools designed through participatory co-creation are better suited to address the unique user needs of pediatric patients.

Keywords

Experience-based co-design · Participatory design · Co-design · Pediatric oncology · Nurses · Empathy · Compassion

Introduction

Medical practitioners of all types face both professional and personal challenges in their day-to-day practice. Because medicine deals with human ailments, there is an emotional component that healthcare workers must take into consideration. Moral support is considered central to the practice of caregiving and care receiving (Kleinman, 2016). Children who suffer from cancer may experience significantly high-state anxiety or depression scores (Patenaude & Kupst, 2005). On the other hand, pediatric oncology nurses suffer from high burnout rates and are extremely vulnerable to its repercussions (Waddill-Goad, 2016), including heightened stress, loss of sleep, and physical and emotional exhaustion. In the clinical encounter, the understanding and practice of empathy has the possibility to protect both the health professional and the patient from personal distress (Ekman & Krasner, 2017).

The overarching goal of our research was to build a tool for the use of nurses and pediatric oncology patients of the pediatric oncology ward of a hospital in Mexico City, Mexico. Nine nurses and four pediatric oncology patients participated in the design of the tool's prototype. The children were all between the ages of 10 and 12 years old. The intention of the tool is to improve communication between pediatric oncology patients and nurses prior, during, and after uncomfortable but necessary medical procedures, such as catheterization, taking medication, and blood drawing. The communication tool is intended to meet the needs of both nurses and pediatric patients along the spectrum of their care journeys by taking into account their emotions during these procedures.

The tool was designed through an experience-based co-design methodology, a scheme supported by ethnographic-based methods (Bate & Robert, 2007), which will be referred to as EBCD (Donetto et al., 2015) throughout this chapter. The research process allowed us to gain access to the users' experiences in order to address the perceived lack of trust and empathy between nurses and the pediatric oncology patients they care for. The final result of this EBCD method was a mobile application that allows users to record and listen to customized audio tapes through a playful and warm visual interface.

Through a series of in-depth interviews based on EBCD with the participants, we determined that the tool would function as a platform for recording and listening to audio material which focused on establishing a narrative to favor the psychological and emotional balance of the patient and nurse (Iyendo, 2017). The tool would thus function as a communication channel that the patient and nurse can relate through and express and process the experiences they share during treatment in a more fluid and playful way (Gilljam et al., 2016) than existing nurse-child patient clinical encounters.

An emotional map was created based on an initial workshop where participants identified the emotions that they feel during different scenarios of their interactions with one another. Based on this data, a low-fidelity prototype (PT1) was designed and evaluated by participants during a second workshop. Finally, this evaluation led to the design and implementation of a high-fidelity final prototype (PT2) (Sanders & Stappers, 2014).

In order to further understand the valuable role users can play in design, this chapter contributes by designing a communication tool that is strongly based on the stated needs and desires of its final users. To the best of our knowledge, this is the first EBCD study focused on healthcare to be carried out in Mexico. The remaining chapter describes our materials and methods, results, conclusions, and discussion.

Literature Review

Illness Narratives

In addition to strictly professional responsibilities, healthcare workers face moral burdens. Acknowledging the personhood of sufferers is a basic moral act in human relationships of all types, including those between patient and physician or caregiver (Kleinman, 2012). The concept of "presence" – moral support given even when nothing practical can be done – is considered central to the practice of caregiving and care receiving, because the interpersonal relationship formed resonates with both parties' understanding of life, self, and dignity (Kleinman, 2012). Children with cancer may experience poor psychosocial adjustment following their diagnosis or during the different stages of treatment, including a significantly high-state anxiety or depression score (Patenaude & Kupst, 2005). Children who lack emotion regulation abilities are more vulnerable to facing psychosocial difficulties during and after treatment, and behavioral interventions targeting emotion regulation skills are believed to reduce the internalizing of symptoms in this population (Katz et al., 2015).

On the other hand, a study carried out in the USA shows alarming results of burnout levels among physicians. As such, 45.8% of physicians reported at least one symptom of burnout (Shanafelt et al., 2012). Burnout refers to overwhelming emotional exhaustion, depersonalization, and feelings of professional insufficiency. Secondary traumatic stress (STS) is a condition characterized by fatigue that can arise from witnessing or listening to accounts of disturbing experiences or traumatic events (Wagaman et al., 2015). Emotionally charged and intense demanding relations are the cause of this grave emotional crisis. Physician burnout and mental distress not only affects the sufferer; it also affects the quality of care that they provide, since it leads to more medical errors (Shanafelt et al., 2010). Nursing is an inherently stressful profession because nurses are overly committed and deal with death and disease on an everyday basis, and they often play the role of peacemaker in an ambiguous hospital environment where uncertainty can cause chaos. Nurses suffer from high burnout and are extremely vulnerable to all of its repercussions (Waddill-Goad, 2016).

Going deeper into demanding and intense relations, physicians, nurses, and patients create one during a health crisis in a rapidly changing environment that includes constant suffering. Emotions run high, the work is intense and overwhelming, and the results can be stressful. This chain reaction has created an increase in burnout, emotional exhaustion, and secondary traumatic stress in caregivers (Yuguero et al., 2017). This relationship between nurses, doctors, and patients creates a complex system which can be easily harmed (Orlando, 2018). Ida Jean Orlando, a renowned psychiatric nurse, theorist, consultant, and researcher, explained that this relationship is a dynamic "whole" and very important ground for professional behavior that needs to be used to help the patient. Nurses who work in pediatric oncology become most distressed when they are unable to provide the high-quality compassionate care that they believe the child and family require (Newman et al., 2018).

Compassion Training

Humans are emotional beings as well as thinking ones. According to Paul Ekman, "emotions are a process, a particular kind of automatic appraisal influenced by our evolutionary and personal past, in which we sense that something important to our welfare is occurring, and a set of psychological changes and emotional behaviors begins to deal with the situation" (Universal Emotions|What Are Emotions?|Paul Ekman Group, 2020). Emotions are a central part of the human experience. They determine how we understand the world and how we interpret the actions of others (The Nature of Emotion et al., 2020).

Dr. James Doty, director of the Center for Compassion and Altruism Research and Education, Stanford University (CCARE), assures that compassion, a multi-textured response to pain, sorrow, and anguish including kindness, empathy, generosity, acceptance, and the capacity to open to the reality of suffering and to aspire to its healing (Strauss et al., 2016), is what will save our species and that this positive emotion is the core of our humanity. Humans are social, sentient beings – through language, we express and transmit information to each other. Some information is easy to express and deliver, and other information is more complex, such as emotions. It is not polemical to say that emotions are sometimes hard to identify in ourselves and in others and even more when we share them. Jean Decety defines empathy as "an inter-subjective induction process by which positive and negative emotions are shared, without losing sight of whose feelings belong to whom," adding that "empathy can lead to personal distress or to empathic concern" (Decety & Meyer, 2008). In other words, in the process of sharing emotions, the intensity of another's negative emotions may lead us to experience pain ourselves.

Empathy in the clinical encounter has the possibility to examine how to enrich a therapeutic relation, benefit the health professional and patient, and protect both from personal distress (Ekman & Krasner, 2017). Neuroscientist Tania Singer states that there is a difference between empathy and compassion: "In contrast to empathy, compassion does not mean sharing the suffering of the other; rather, it is characterized by feelings of warmth, concern and care for the other, as well as a strong motivation to improve the other's wellbeing. Compassion is feeling for and not feeling with the other" (Singer & Klimecki, 2014). Understanding the nature of this important social emotion is crucial to identifying its positive impact on our human behavior (Yongey Mingyur et al., 2007).

Neuroscientists and psychologists have recently shown interest in the study of compassion in an academic way, understanding it as the contemplative science that refers to interdisciplinary scientific approaches to the mind and mental training based on traditional Eastern contemplative methods and philosophy (Kemeny et al., 2012). In the classic contemplative tradition of Buddhism, the study of mind, compassion, and meditation in compassion has been observed for centuries. Dharma, the teachings of Buddha, believes that the basic nature of all sentient beings is goodness. Compassion takes this capacity to look at another sentient being as equal to oneself and further. Since one of the current theories of modern physics holds that all matter was connected as a single point at the start of the Big Bang, it is theoretically possible – though as yet unproven – that whatever affects one particle in our universe also affects every other one (Yongey Mingyur et al., 2007). This entanglement creates connections we observe between individuals when sharing deep emotions.

The idea of being able to help others and share their emotions can become difficult when it comes to the sharing of suffering. When exposed to constant distress, the distinction between self and other becomes blurred, and managing this emotion becomes challenging, especially for professionals in healthcare institutions (Singer & Klimecki, 2014). Compassion is a convenient tool when handling a crisis (Wagaman et al., 2015).

Studies show that, applied correctly, compassion can be used to prevent negative emotions that emerge during a crisis and the constant exposure to the suffering of others (Davidson & Harrington, 2002). Many benefits have been found upon cultivating compassion in the clinical encounter, chiefly that communication through empathy can improve patient outcomes (Neumann et al., 2009). Compassion can be taught; our brain can form new connections to produce new cells as well as sculpt existing connections. This is called neuroplasticity. When our brain faces a new challenge, it reorganizes and restructures to respond to that situation. In addition, our brain learns more established pathways and successful emotional regulation and creates a healthy habit (Davidson & Lutz, 2008). There is evidence that shows a change in neural responses to suffering in individuals who were taught compassion training and a new coping strategy that fosters positive affect even when confronted with the distress of others (Klimecki et al., 2013). Furthermore, increased altruistic behavior after compassion training was associated with altered activation in brain regions implicated in social cognition and emotion regulation. These results suggest that compassion can be cultivated with training and that greater altruistic behavior may emerge by understanding the suffering of other people (Weng et al., 2013).

In his research, neuroscientist Ezequiel Gleichgerrcht posits that for medical practitioners, it is important to understand where the pain comes from in order to develop strategies that prevent them from having emotional burnout. Gleichgerrcht concludes that professional experience seems to desensitize physicians to the pain of others without necessarily helping them down-regulate their own personal distress. Minimum levels of empathy appear necessary to benefit from the positive aspects of professional quality of life in medicine (Gleichgerrcht & Decety, 2014).

EBCD

Though children's right to participate in their own healthcare is an issue which has gained traction in research in recent years, their participation is unsatisfactorily applied in praxis (Gilljam et al., 2016). Gaining a better understanding of children's own perspective on how their participation can be promoted in healthcare can lead to a more qualitative and appropriate care for pediatric patients (Gilljam et al., 2016). By basing their design approach on constructivist grounded theory, a researcher can attempt to understand experience and its meaning in the same way as participants (Charmaz, 2014), particularly in the multiplicity of experiences.

The concept of experience-based co-design (EBCD) refers to the gathering of multiple and varied experiences from participants to identify key "touch points" – emotionally significant points – and assign positive or negative feelings to them it has its origins in both the design and social sciences. It's a commitment to allow participants to become designers of their own experience (Bate & Robert, 2007). In addition to a focus on experience, EBCD aims to engage users in the design process through their active participation as co-designers (Donetto et al., 2015). Although the results of EBCD are mostly small-scale changes within one service area, they have been found to be immensely valuable to patients (Robertson et al., 2012). From the perspective of adhering to inclusive design principles (Rioux, 1996), we have conducted research and design on a hard-to-reach and often excluded grouping in healthcare and services research (Treviranus, 2019) – children who are in various points along their healthcare journeys, from initial diagnosis to treatment, remission, and relapse.

An example of the implementation of EBCD is the case of the UK-based User-Centered Healthcare Design (UCHD), a team of design and healthcare researchers and practitioners who develop methodologies for healthcare service design. Their approach has a focus on people's lived experiences and a commitment to participation in the process of design, as a means of ensuring that what is designed is relevant to the practices, needs, and values of participants. Through EBCD, the UCHD works together with patients, caregivers, and staff. Rather than being a single prescriptive method, EBCD provides a range of techniques and tools within a four-phase structure where participants work together to capture and then understand their lived experiences of healthcare in its multiplicity, improve a service based on this understanding, and measure the effects of these changes (Bowen et al., 2013).

Materials and Methods

Having understood that empathy and compassion can be useful in addressing the particular distress experienced by patients and healthcare professionals, our study aimed to create a communication tool that would improve the relationship between pediatric oncology patients and nurses working in the pediatric oncology ward of a hospital in Mexico City, Mexico. We decided to approach the design through a participation-based method (Fig. 1).

Interviews with Field Experts

The first step in our methodology was to conduct a series of interviews with field experts, where we were able to discuss topics such as emotions, the role and importance of compassion in the treatment of pediatric oncology patients, and all topics of interest in this chapter (Sexton, 1980).

The interviewed field experts were Mariana Campos, the psychologist working at the pediatric oncology ward of the hospital where this research was conducted, and Emiliana Rodríguez Morales, who holds a Master's in Mind, Brain, and Education from Harvard University and a Bachelor's in Physics from the National Autonomous University of Mexico. Mariana Campos participated in four sessions, in which she provided insights to the researcher on patient journeys in the hospital and the complex and varied relationship between pediatric oncology patients, their medical team, and their families. Emiliana Rodríguez Morales participated in two sessions, in which she provided insights on working with children and their emotions, evaluated the research design that had been created in collaboration with Mariana Campos, and

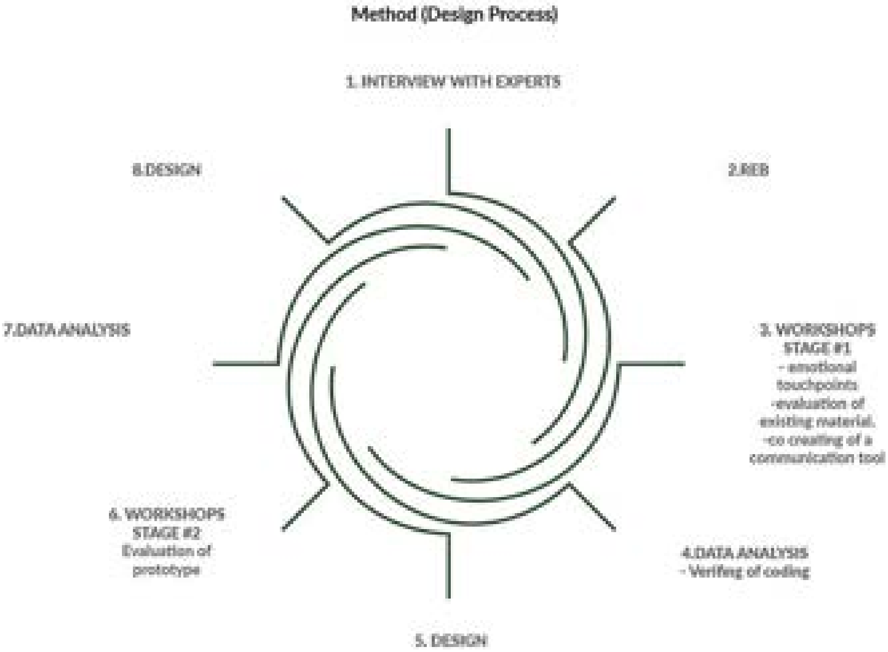


Fig. 1 The EBCD methodology employed in our research, in chronological order: (1) interviews with experts, (2) REB, (3) workshops stage #1, (4) data analysis – verifying of coding, (5) design, (6) workshops stage #2, (7) data analysis, and (8) design

suggested that the employed emotional vocabulary be widened to capture the range of children's experiences.

REB Approval

The second step was obtaining written approval from the Research Ethics Board (REB). The application process was meticulous and relatively long because children and nurses – the key subjects of our research – are emotionally vulnerable. In seeking REB approval, our main concern was to avoid becoming a source of stress for the children or nurses, as working with emotions can sometimes result in an emotional state or crisis. Psychologist Mariana Campos, who had previously treated all pediatric patients involved in this research, was present during our work sessions with all parties and was fully prepared to lead any necessary intervention. These ethical concerns led us to create multiple workshop sessions for our research, in order to separate nurses and children, allowing children who felt indisposed to postpone the session and nurses to be divided into groups to avoid heavily affecting their workload.

It was also decided that the researcher would not interact directly with the patients or nurses. The researcher acted as an observer, and psychologist Mariana Campos directed all sessions. To avoid overwhelming the participants, the duration of each work session was 60 min or less, as determined by the psychologist. Nurses participated voluntarily and were informed of the research protocol through an informed consent form. The pediatric oncology patients who participated were selected by the psychologist, and a consent form was signed by their parents. When working with the pediatric oncology patients, all questions and comments were made through play and words appropriate for their age, which they understood, and which did not generate confusion or stress. The children were informed that they could stop the session at any moment. The workshops took place in an area of the hospital already familiar to the participants*. Only audio was recorded during the sessions; no video or photographs were taken. This REB approval was obtained on November 11, 2019.

* Note: Due to the unexpected situation relating to the COVID-19 pandemic, some workshops were conducted virtually.

Workshops

The psychologist conducted the workshops while the researcher took field notes, recorded the sessions, and collected the materials created by the children and nurses. As observed in Dewar's (2010) research on the use of emotional touch points as a method of tapping into the experience of receiving compassionate care in a hospital setting, this method helps people to get in touch with their own experience. It also enables the development of relationships with patients, families, and staff (Dewar et al., 2010). Participants were therefore invited to engage with emotional touch points, pairing emotions with touch points or experiences during hospitalization, such as surgeries, chemotherapies, consumption of medication, and canalization, among others (Dewar et al., 2010), as well as activities that involved evaluating the existing didactic material tools and designing, drawing, or otherwise explaining their ideal toy or tool (Sanders et al., 2010). The analysis of the workshop led to exploring more profound issues during the following session (Charmaz, 2014) (Fig. 2).

The first workshop was conducted with the aim of identifying and understanding the needs and emotions of all participants. This was the first stage of co-designing the communication tool. The workshop consisted of three activities:

Activity 1

The participants were presented with three different types of materials that have been used in the past to discuss the following: What didactic tools have been presented in the past that have been useful and which ones haven't and why? What characteristics do they believe are key to creating a successful communication tool? These were discussed using age-appropriate language.

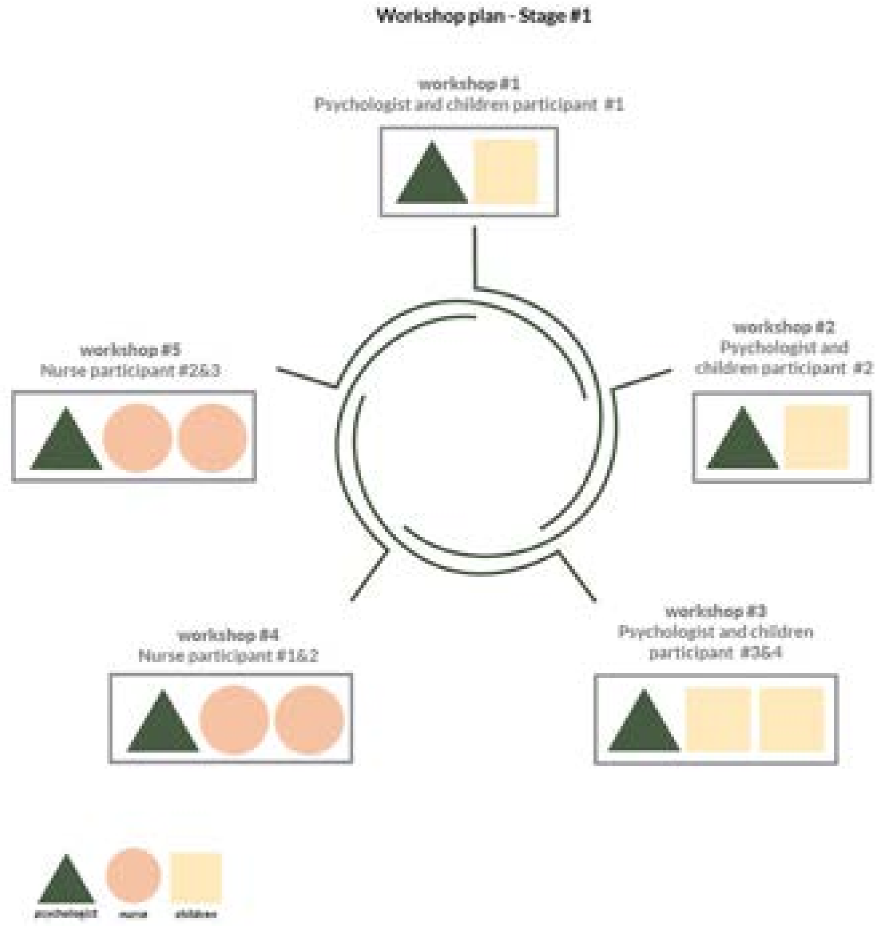


Fig. 2 The structure of the first round of workshops

Activity 2
The participants were presented with a timeline of their hospitalization process and for the nurses of their journey with their patients with an emotional vocabulary to pair with crucial moments.

Activity 3
The objective of this activity was to gather characteristics for the new communication tool. The nurses were asked to write words or sentences describing what the communication tool must solve, be like, and communicate. What affordances the communication tool must have and adjectives describing what it must not be according to the pediatric oncology patients.

Overall, the three activities were designed to take into account psychologist Mariana Campos, Emiliana Rodríguez Morales, and the researcher’s observations that it is not wise to overstimulate the children's senses, and to avoid incorporating the sense of smell into any activities designed. In addition, visual stimulation should be very subtle and abstract, and concentrating on graphic stimulation should be avoided. The nurses were concerned with the isolation kids experienced and said that, in their experience, video games disconnect them further, causing them to neglect their everyday routines during hospitalization.

Participants

Four nurses and four children were invited to participate in our Participatory Designing Workshop (Robertson et al., 2012) in the oncology ward of the hospital, located in the Observatorio neighborhood of Mexico City. The nurses are all employed in the pediatric oncology ward. All four nurses are females between the ages of 25 and 65.

The pediatric oncology patient participants were three females, two of 10 and one of 12 years of age, and one male of 10 years of age. They have all been diagnosed with cancer or are in need of a bone marrow transplant. The age range of the children was chosen for two reasons. First, it was considered by the hospital staff to be an age range within which children will be most responsive to this play-workshop environment and able to communicate their thoughts and express their preferences for communication tools. Second, because in this particular hospital the majority of the pediatric oncology patients are within this range, it is believed that new communication tools will have a positive impact on the children and meet their varied needs.

Originally, four workshops were planned, but due to the health situation the children were facing and the tight schedule the nurses work under, the workshops were divided. Three workshops were done with the children, one where two participants took part in an individual workshop, and another where two participants engaged in the workshop together. With the nurses, we divided the workshops into two, where one was held with transplant pediatric oncology nurses and the other with pediatric oncology nurses.

Psychologist Mariana Campos invited nurses and pediatric oncology patients to participate by playing an active role in the creative process (*Making Emotional Connections Through Participatory Design – Boxes and Arrows*, 2002), through workshops aimed at developing a new communication tool intended to improve the nurse-patient interactions during painful oncology procedures. These workshops were held at the hospital. Psychologist Mariana Campos selected patients, considering that they were suitable to participate in the sessions based on her professional knowledge of the patients' states and fitting the strategies to the particular specific research participants (Charmaz, 2014).

Analysis

Our analysis involved different steps. First, a read-through of collected field notes and open discussion sessions with psychologist Mariana Campos. Second, a session of coding systematic code through content analysis took place. There were two coders; we used the software NVivo12 to carry out the coding digitately. The session involved a categorization of themes that led to the first findings of the nature of the prototype. The material created by children and nurses (see Fig. 3) was analyzed, grouped by themes, and categorized to identify the relationship between the emotions presented by the children and the nurses during the same experience or touch point. After coding was finalized for the purpose of triangulation and verification of the coding, a session with Emiliana Rodríguez took place to analyze the focus of the research and the nature of the prototype. We report on these findings below.

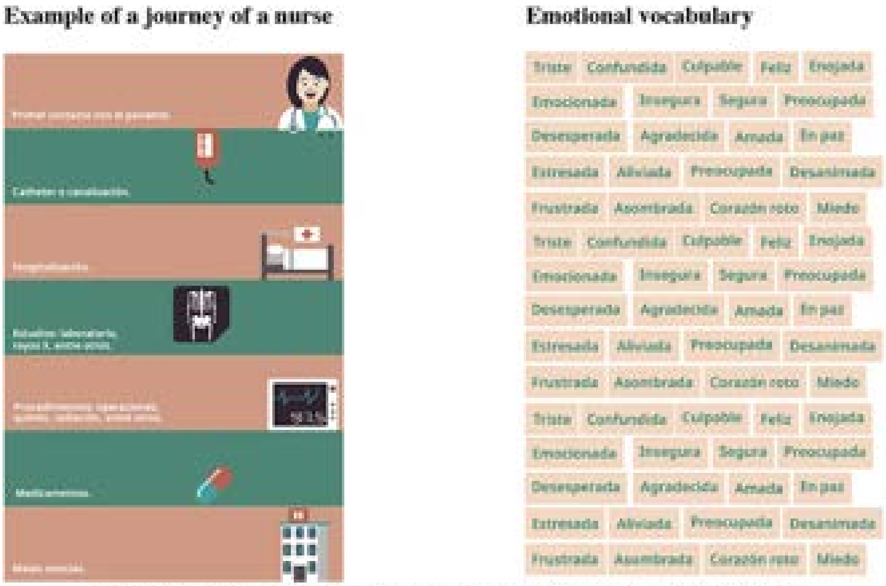
Findings

In their work, Simon Bowen, Kerry McSeveny, Eleanor Lockley, Daniel Wolstenholme, Mark Cobb, and Andy Dearden (2013) reported initial concerns about activities being "daunting" to participants in their study. After their workshop, participants agreed that sharing their experiences "helped to build empathy and cohesion in the project group." Also, as in their research implementing patient-centered cancer care: "using experience-based co-design to improve patient experience in breast and lung cancer services, the majority of our participants nurses and children felt vulnerable at certain points in the pathway" (Tsianakas et al., 2012). In our workshops we found that participating children also experienced points in their care journeys when they were vulnerable by virtue of feeling isolated and lonely. We found that the children and the nurses trust that the hospital, health professionals, and the treatment prescribed are adequate and helpful and that their stays in the hospital are necessary. However, the children don't feel an emotional connection with the nurses. They don't feel they are a team. Among the many emotions mentioned by the children, isolation and loneliness are deep emotions that indicate their need and longing for human contact (Fox et al., n.d.). We observe that emotions come from both physical pain and emotional pain (Weissbourd, 2009).

Below, we have divided our findings into two categories. First, we present the children's responses to the activities. Second, we present the conclusions of the nurses after participating in the activities, using the most representative examples of their responses.

Children

The aim of the first activity was to identify and understand the prevailing emotions displayed by children during their hospitalizations (*Toolkit*, n.d.). This emotional mapping exercise was used to invite the patients to reflect on the emotional impact of the touch points along the pathway (Bate & Robert, 2007; Dewar et al., 2010). The most common emotions shown by children during hospitalization processes are fear and worry: 50% of pediatric oncology patient participants feel worried and sad when they receive the news that they will be hospitalized, and mostly all emotions they feel they say are negative. When they are canalized or in a catheter process, three out of four children feel fear. One participant expressed that she feels secure because she feels safe, but the rest of the emotions are negative, like worry and desperation. During hospitalization, three out of four children feel sadness. Other feelings expressed are anger, discouragement, and confusion. One participant says she feels safe in the hospital but, at the same time, stressed and with fear. While taking labs,


Example of a journey of a nurse

Emotional vocabulary

Example of an emotional map created by a pediatric oncology patient:

Fig. 3 An example of an emotional map and the tools that were used by the participants

three out of four children feel fear and two out of four feel nervousness. During surgeries, chemotherapy, and radiation, two out of four participants feel fear and confusion. The emotions that the children feel while taking medication were different for each one. Three out of four of the children associated taking medicine with strong negative emotions such as anger, desperation, and discouragement. Two out of four children said they feel at peace, especially when they finish taking them all. One participant expressed only positive emotions, like a sense of security and peacefulness. When given bad news, all four children felt strong negative emotions such as sadness, fear, concern, frustration, and desperation. Two out of four children felt sadness.

The aim of the second activity was to analyze the preexisting didactic material available to the children within the hospital (Sanders et al., 2010). Reflecting on this, the four children who participated in this study stated that they enjoy playing with toys during hospitalization. All four had brought some of their favorite toys from their homes to the hospital. Some mentioned that they faced problems bringing them into the hospital due to safety concerns. They stated that this personal object serves as relief. The participants did not show deep interest in reading or looking at illustrated books during hospitalization. They do not talk much about technology, though participant #2 mentioned that what is most enjoyable for her is playing online games with her friends.

The aim of the third activity was to co-design the new communication tool (Sanders et al., 2010). All four pediatric oncology patient participants said that what helped the most during painful and complicated procedures was being close to their mother, with some mentioning their father as well. They also mentioned that the saddest moment is being separated from their parents and their siblings, friends, and grandparents. One participant also mentioned her pet. They all drew toys and security objects such as stuffed animals and blankets they had during their hospitalization. All these objects were brought from home by the pediatric oncology patients. One girl drew a pizza because "it was the only dish that never changed flavor," so we associate this with comfort of something she knew or relied on. When one participant drew her family, she drew hugs and holding her mother's hand while in pain. Participant #2 stated: "in fact, every time I'm punctured, I lean on mom, I hug her and close my eyes."

Nurses

The aim of the first activity was to identify and understand the emotions presented by nurses during the children's hospitalizations (Bate & Robert, 2007; Dewar et al., 2010) and to involve them in a collaborative identification of areas of opportunities and possible solutions (Iedema et al., 2010). When the nurses have their first contact with a new patient, three out of four nurses report feeling positive emotions such as happiness and excitement. Three out of four feel excited by the idea of meeting a new patient and look forward to it. One nurse experiences only negative emotions since she does not like working in the pediatric ward and prefers working with adults.

Below are some testimonies which are representative of the general responses we obtained from nurses.

Nurse #2: *And well, the hospitalization part is sometimes sad because they stay for many days. They feel, I don't know, like locked up. It sometimes is very difficult for them to have contact with me because they do not see me due to my mask and medical gear. It is very difficult to show your emotions through your eyes. Well, that part has caught my attention a lot. Because they don't know that I am smiling at them or that you are doing something even though they don't look at you. I don't know. I feel that communication is broken and the relationship with the patient is cut. Because you don't see each other well. You only see the other person's eyes.*

Nurse #4: *I have mixed feelings about medication. One, I'm grateful if parents cooperate. If they help us. It is easier, less traumatic, and less complicated for the child. But also, angry because children are the reflection of adults. If the child has tantrums and does not cooperate, we still have to make them take the medicine. That's when the nurse becomes rude and ugly, when she doesn't speak nicely, when she doesn't know, when she can't.... And that leads us to many medical errors too.*

The aim of the third activity was to co-design the new communication tool. Nurses stated the following in response to the question: What should this communication tool solve and communicate?

1. Resolve attitude
2. Security
3. Interpretations
4. Availability
5. Resolve doubts
6. Communicate education and information among staff
7. Effective communication
8. Resolve honesty
9. Resolve conflict between us

Nurses stated the following in response to the question: What affordances should it have?

1. Attitude
2. Companionship
3. Emotional help
4. Teamwork
5. Flexibility; not so many limits
6. Empathy
7. Consistency and communication between interdisciplinary team
8. Knowledge and education

Nurses stated the following in response to the question: What should the tool avoid?

1. Representation of angry or stressed nurses
2. Representation of needles

3. Representation of nurses who don't know
4. Crying children
5. Closed rooms

Design of Prototype

The design process for this prototype involved the four stages described by Sanders and Stappers in their work. These include probes, toolkits, prototypes, and four approaches: pre-design, generative, evaluative, and post-design. Within this process, nurses and pediatric oncology patients are active participants in the generative and evaluative stages through a series of interviews and trials of the prototype (Bate & Robert, 2007).

Additionally, the strengths and limitations of the available didactic materials were determined in the workshops. Materials such as books and toys worked well as complements to psychological therapy; however, the nurses don't have access to these materials. The objective was to design a tool that facilitates an emotional connection being formed between the nurses and pediatric oncology patients. Books and toys do not engage both parties and, therefore, they do not serve that purpose. Additionally, the accessibility of these materials is limited, as they are prohibited from certain areas of the oncology ward for hygiene purposes.

On the other hand, the nurses stated that their main task is to ensure their patients cooperate with them and abide by their routines and that this becomes difficult to accomplish when pediatric oncology patients do not trust or feel an emotional connection to them. However, the nurses have little free time to devote to devising activities that enable them to bond with their patients.

In response to the above-mentioned findings, we determined that the prototype would be an application, accessible from smartphones, and based on sounds rather than images (Iyendo, 2017). Research has been conducted on the subject of the use of music and sound therapy to alleviate stress and improve immune system function. It has been widely documented that stress can be suppressive of various aspects of the immune response (Brennan & Charnetski, 2000). In modern times, music is used in many facilities such as hospitals, nursing homes, schools, and clinics to help combat a variety of problems, including anxiety. Relaxing music helps slow down heart rates, breathing, and thinking and enables a person to reach a deeper level of rest and tranquility. It therefore can become a key tool to help relieve stress and calm the mind (Clements-Cortés, 2013). However, we recognize that deploying a sound-based approach provides a limitation in terms of inclusivity, and future research and design will take into account the needs of hearing-impaired children in order to support them in their pediatric oncology care journeys.

The nature of the initial app is based on establishing emotional connections between the participants (nurses and their pediatric oncology patients), allowing them to discover the touch points in which they often feel the same emotions. Smartphones were found to be possessed by the parents of even the most underprivileged pediatric oncology patients, as well as by all of the nurses of the oncology ward. All parents and nurses interviewed were familiar with smartphone applications and were able to operate them. Therefore, they were determined to be an accessible tool that does not require additional time spent on specialized training for these participants. During interviews, pediatric oncology patients stated that they feel good when they seek contact with the people they love or when they are in contact with positive objects, they are familiar with. It was therefore determined that the application would be used prior, during, and after painful and stressful procedures that the nurses administered to the children, such as vaccines or the taking of blood samples. The application would allow the nurse and the pediatric oncology patient to connect on an emotional level before these procedures, establishing touch points of compassion and empathy between them. It is through design that we can add spirit and aesthetic to the equation of good engineering (*Programmers, Designers, and the Brooklyn Bridge|Scott Berkun*, n.d.).

Mobile applications for meditation or music listening, such as Headspace or Spotify, are widely available. This prototype is instead focused on establishing and nurturing a personal relationship of trust and an emotional connection between the nurses and the pediatric patients of the hospital's oncology ward, through customizable voice messages that can be recorded by both parties. The shapes and colors displayed in the user interface were muted to avoid overstimulating the users (Fig. 4).

Results and Discussion

Prototype #1 (P1)

The application features a Welcome page that displays two options: Instructions (which can be skipped) and Start. By clicking Start, the user is taken to the Home page, which is divided into three sections: Create, Listen, and Reflect. Instructions are available for all three sections, and there is an option to skip the instructions. The instructions can be read or heard in order to ensure accessibility.

The first section, Create, is divided into two sections: one that enables the user to record with or without background sounds and another that records agreements, where the pediatric oncology patient and nurse can record themselves stating mutually beneficial agreements. Once the user has recorded something, they are automatically taken to the Listen section. The Listen section allows the user to play the different recordings they have saved, organize their order, and create playlists. The final section, Reflect, allows the user to evaluate the recordings and reflect on where and when the application was used and whether they found it useful.

Evaluation of P1

A workshop subdivided into six sessions was conducted to test the first prototype (P1). The children interacted with the prototype and after this psychologist Mariana Campos engaged with some questions. The questions we asked the pediatric oncology patient and nurse that were invited to engage virtually with P1 were based on the

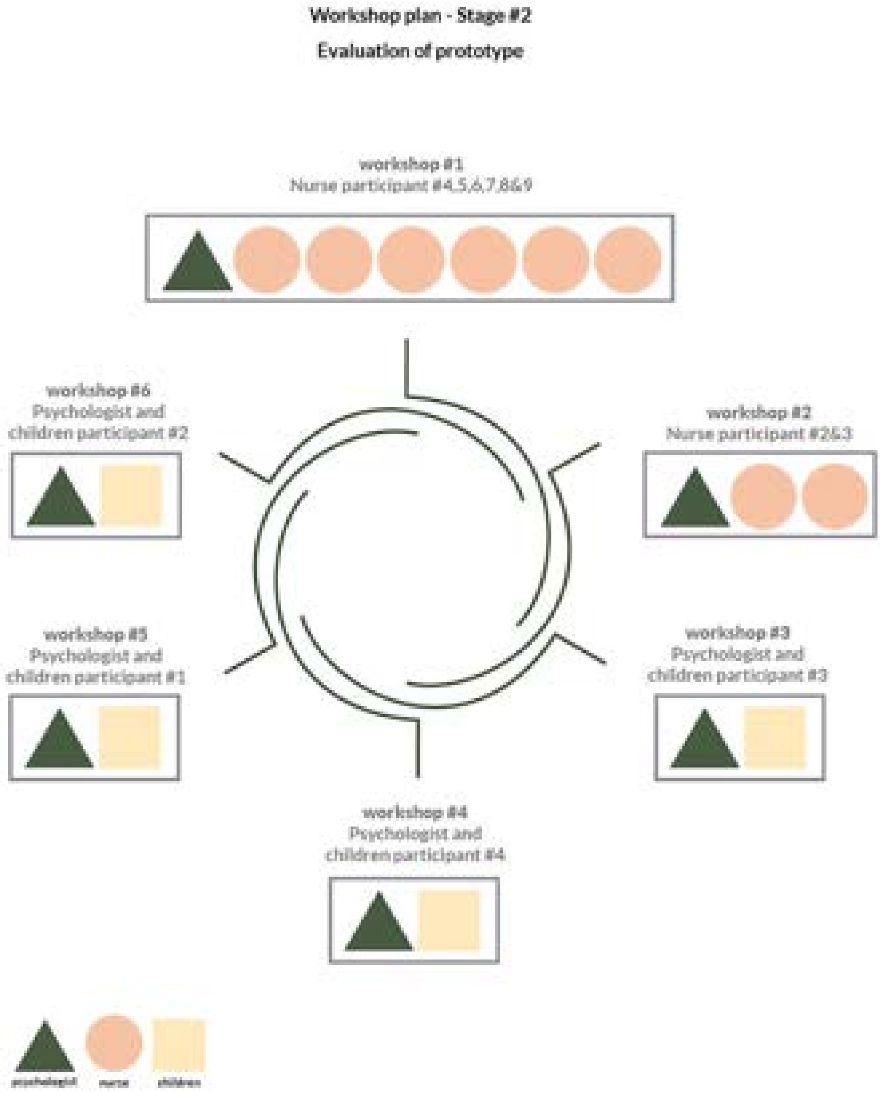


Fig. 4 The structure of the second round of workshops

three elements of good design by essays on design engineering and project management (*Programmers, Designers, and the Brooklyn Bridge|Scott Berkun*, n.d.). The following are the examples of the questions:

1. Is this mobile app easy to navigate?
2. Did you understand the instructions?
3. Do you like it, and would you use it?
4. What would you change?

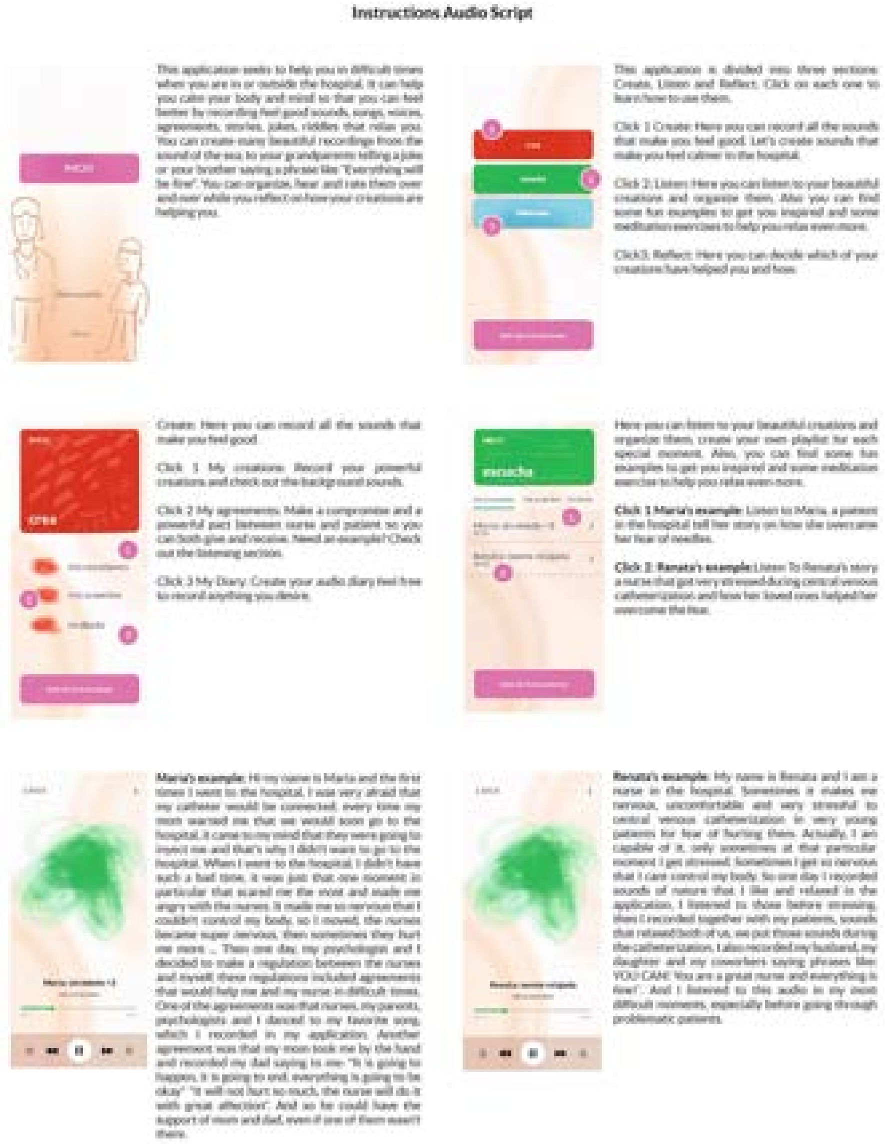


Fig. 5 Description the instructions audio script

The following are the most relevant takeaways from the interviews (Fig. 5).

Workshops #1 and #2

For the first workshop, six nurses were invited to engage with P1 and later interviewed on their opinion (*EBCD: Experience-Based Co-design Toolkit|Point of*

Care Foundation, n.d.). The second workshop repeated this dynamic, with two nurse participants. The questions were asked openly, and the participants were invited to answer freely as a discussion.

As a group, all six nurses interviewed agreed they liked the idea of an application using personalized sound recordings to help them connect with their patients, though some concerns were raised about presenting themselves as vulnerable to the children, as well as about time constraints in their tight schedules. The group agreed that P1's user interface was legible and easy to navigate. Regarding the P1 graphic design, all six nurses agreed that they would like the colors to be brighter and for the design to be more child-friendly by integrating illustrations or animations. Regarding the integration of pre-recorded meditations and breathing exercises to the prototype, the majority of the nurses interviewed agreed that they are interested in using an application to relax and be in touch with their emotions.

Through this interview, it was determined that an introduction on the topic of compassion should be added to the application. This could take the form of an animation to motivate the pediatric oncology patient and to establish a connection between them and with their own emotions. It was also determined that following interviews should focus on collecting more personal stories from the nurses to analyze.

The feedback from the second workshop, with two nurse participants, was similar to the answers recorded in the first workshop. Both nurses agreed that the tool would be useful to them and that establishing an emotional connection with their patients would help them carry out their work. They agreed that the prototype was simple to navigate and suggested the word "Reflect" be changed to something more child-friendly. Both nurses suggested more colorful shapes for the design.

Workshops #3, #4, #5, and #6

For workshops #3, #4, #5, and #6, four pediatric oncology patients were invited to engage with the prototype and later interviewed on their opinion, individually. Each workshop interviewed a different pediatric oncology patient. The interview questions were the same as those asked in workshops #1 and #2.

All four pediatric oncology patients agreed that they liked the idea of the application. The two pediatric oncology patients in remission stage liked the initial design's muted color scheme: the other two stated they would prefer livelier colors and shapes. All participants agreed that they found the application easy to use; one pediatric oncology patient stated there were words they did not understand, but that they would ask their parent or guardian to explain.

Prototype #2 (P2)

The evaluations of P1 served to create a second prototype, with the following improvements.

Color Palette

The first color palette was chosen in a low-intensity hue based on psychologist Mariana Campos' expertise and experience with didactic material to induce a calm mental state and to invite the participant to partake in the action of interiorizing. Taking into account the evaluation of the first prototype, we made the colors less mild and more attractive based on the pediatric oncology patients' and nurses' descriptions of what color palette they would like (De et al., 2018).

Script

Considering the results of the evaluation of the prototype and the suggestions given, we made changes to the script. We summarized the instructions based on the understanding that both pediatric oncology patients and nurses found the app intuitive while interacting with it, and the excess of instructions was not needed.

Illustrations

In response to the suggestions to make the prototype more user-friendly, we created some illustrations of a nurse and a child and added more texture to the background. The interaction and structure of the app stayed the same since they were able to interact and understand it easily (Figs. 6 and 7).

Discussion

Experience-based co-design (EBCD) engages users by gathering their experiences and taking them into account, thus making them active participants in the design process (Donetto et al., 2015). Our study aimed to create a communication tool that would improve the relationship between pediatric oncology patients and nurses working in the pediatric oncology ward of a hospital in Mexico City, Mexico.

We interviewed field experts who helped outline two workshops, where participants were able to provide key insights on their experiences and needs, from which we built an emotional map that elucidated the main concerns that the communication tool would address. The next stage involved analyzing the collected data and designing the initial prototype (P1). In this stage, it was determined that P1 would be a mobile application based on sounds, to avoid overstimulating the participants' visual senses, which psychologist Mariana Campos has found in her work in the hospital to trigger emotional responses more easily than other senses. Based on psychologist Mariana Campos' observation that children can enter a melancholic emotional state after a visually stimulating video call with their loved ones, we ensured that the interface of P1 maintained their awareness of their hospital surroundings. By only incorporating sounds into P1, we grant participants control over what to record, manipulate, or erase, enabling them to choose what relaxes them. Nurse participants mentioned that pediatric oncology patients appear isolated after they spend prolonged time interacting with screens and that this makes it difficult for

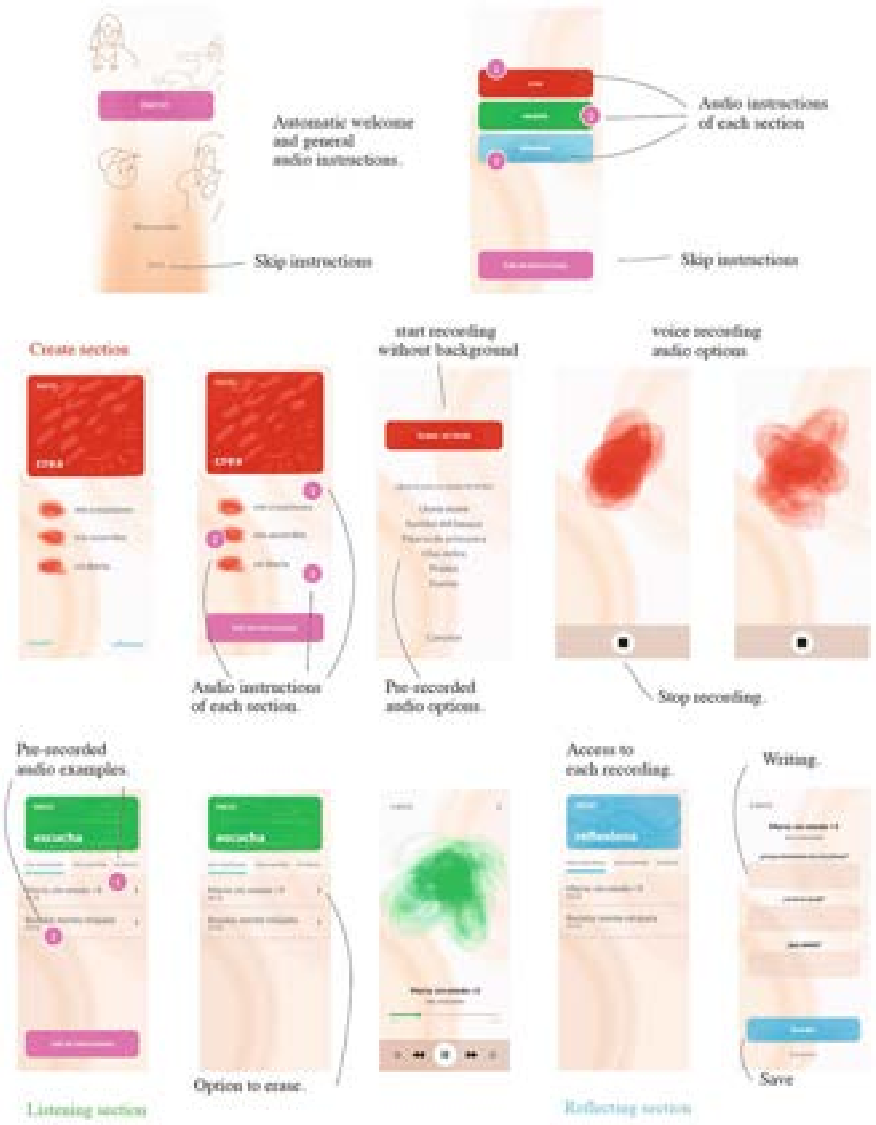


Fig. 6 The final prototype

the nurses to connect with them. For this reason, P1 is intended to be low interaction in front of the screen.

The nature of the P1 application is intended to help establish an emotional connection between pediatric oncology patients and nurses of the pediatric oncology ward, to generate an affective bridge of communication between patient and nurse by using technology – which is something that children currently value and are familiar

Fig. 7 A comparison between Prototypes #1 and #2.

with – and to support the nurses in the daily procedures they are tasked with by creating communication strategies. An example of these strategies is the possibility of recording verbal agreements through the application. In order to cooperate and form a healthy relationship, first both parties should avoid being in a state of alert or stress. Connection is very difficult to accomplish in a state of alertness, stress, worry, or anger (Fox et al., n.d.). By accessing relaxing sounds or the sound of a family member through this application, we hope to lower this state of anxiety in participants, so they can then begin making agreements and forming an interpersonal connection.

The second workshop consisted of allowing participants to test the prototype and then collecting their feedback. The data was analyzed and employed to create a second prototype (P2). From the participants' feedback, we concluded the following:

- P1 responded to the pediatric oncology patients' feelings of isolation and nostalgia by allowing them to record custom audios of their loved ones and reminders of joyous memories.
- It allowed pediatric oncology patients and nurses to have a moment in which, together, they established and recorded agreements through negotiations, to listen back to them during painful or difficult procedures. In this way, the nurse and patient had a space for connection that was mediated by a concrete tool which was used equally by both participants, because the interface is the same for children and nurses.
- The design is flexible so it can meet the changing needs of children depending upon where they are at in their care journeys.

To the best of our knowledge, there is no literature in Mexico that addresses emotional processes through an EBCD methodology. Our findings showed that all participants recognized the necessity for a communication tool, were eager to participate in the design process, and found the resulting prototype to be engaging and helpful. Moving forward we intend to continue to update the mobile app.

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Part IX

Poverty and Economic Inclusion

Poverty and Economic Inclusion: Introduction

57

Stefan Tromel

Abstract

The statistics show that persons with disabilities have lower levels of lower market participation than the rest of the population and are also often not covered or at least not adequately covered by social protection. The five articles in this section of the handbook provide a complementary perspective on the barriers faced by persons with disabilities both in developed and in developing countries in the access to their rights to employment and social protection, rights enshrined in the CRPD. Recommendations are made for policy makers to reduce the gaps persons with disabilities face in the enjoyment of these rights.

It is a generally accepted fact that persons with disabilities are overrepresented among persons living in poverty and extreme poverty. Two of the main reasons for this are the lower levels of employment and insufficient access to social protection. It is therefore not surprising that the different contributions in the chapter on poverty focus on employment and social protection.

The statistics available in the International Labour Organization from almost 100 countries show that there is a gap of 30–40% in the labor market participation of persons with disabilities compared to persons without disabilities and this gap exists in all regions of the world. The gap between women with disabilities and women without disabilities is similar, but as the overall labor market participation of women is lower than that of men, the rates of women with disabilities are lower than those of men with disabilities.

When in employment, persons with disabilities are overrepresented in self-employment and in informal employment compared to persons without disabilities.

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There is also a salary gap for persons with disabilities which in the case of women with disabilities is compounded by the gender wage gap. A particularly concerning statistic shows that youth with disabilities are twice as likely to be in neither employment, education, nor training (NEET) than youth without disabilities and this is so across all regions.

Enjoying the right to work and employment remains a persistent challenge for many persons with disabilities, and there are many factors that contribute to this. The UN Convention on the Rights of Persons with Disabilities (CRPD) reminds us that all rights covered by the Convention are interrelated and indivisible and Article 27 on work on employment is a good example of this. When persons with disabilities don't have equal access to education, when some persons with disabilities are denied their legal capacity, and when public transport, buildings, and information remain inaccessible for many persons with disabilities, all these rights violations have a significant impact on the opportunities for persons with disabilities to enter and stay in the labor market, but also in ensuring that they have equal opportunities in accessing decent work, the ILO terminology which is now also reflected in goal 8 of the Sustainable Development Goals.

A particularly important relationship exists between social protection and employment. Too often, social protection systems are designed based on the assumption that disability means inability to work. While social protection plays a key role to protect persons with disabilities, like many others, from poverty, the benefits provided should focus on the additional costs faced by persons with disabilities and should be compatible with income resulting from work or other support that addresses poverty, unemployment, etc.

When looking at legislation, policies, and programs that seek to promote the employment of persons with disabilities, it becomes clear, as shown by the different contributions in this section, that there are huge differences between those countries where the majority of the working-age population works in the formal economy and those countries where the majority, and often the vast majority, of the working-age population works in the informal economy. The usual catalogue of measures that we are familiar with (non-discrimination legislation, quota systems, and other affirmative action measures) are often not relevant in the context of the informal economy, and more efforts need to be made to design policies that are tailored to this situation. And let's not forget that 60% of the workers worldwide work in the informal economy.

As reflected in the UN CRPD and in line with other rights enshrined in the Convention, more efforts need to be made to ensure full inclusion and participation in the mainstream solutions that governments put in place to increase labor market participation. An example of this are measures to increase employment of youth in the digital and green economy which need to be inclusive and accessible to young women, men, transgender, and gender non-conforming people with disabilities. Still too often, the focus is on specialized and separate measures focusing on persons with disabilities which, even when well designed, can only make a small contribution to addressing the employment gaps faced by persons with disabilities.

On a more positive note, the last years have seen an increased interest of the private sector in the employment of persons with disabilities. A still small but rapidly growing number of global and national companies have realized the benefits of employing persons with disabilities. Supported also by the ILO, there are more than 35 national employer-led networks bringing together companies, both local and subsidiaries of global companies, committed to the employment of persons with disabilities. An area that deserves more attention is how governments and also these networks can provide more support to small- and medium-sized enterprises, including those that operate in the social economy.

The contribution from Gertrude Oforiwa Fefoame and Hannah Loryman focuses on the recently adopted General Comment No. 7 of the UN Committee on the Rights of Persons with Disabilities related to Article 27 of the CRPD. Nobody better placed to do this analysis, as Ms. Fefoame was the chair of the working group of the CRPD Committee which led the work on this General Comment. The chapter provides an overall description of the General Comment and focuses in particular on some of the less explored or more challenging elements of Article 27. Ensuring that the discrimination based on disability includes persons who are associated with a person with a disability and who might be discriminated because of this association is a very important and welcome clarification of the article. The challenges and opportunities of a rapidly changing labor market, the need to focus on persons with disabilities in the informal economy, and the impact of unpaid care especially on women with disabilities are other important elements of the new General Comment explained in this contribution. Finally, also addressed in this contribution is how to deal with sheltered and segregated employment, one of the most debated elements in the discussions that led to the adoption of the General Comment.

The contribution from OECD experts Silvia Garcia-Mandico and Christopher Prinz provides a very good analysis of the interaction between poverty and employment and makes very relevant recommendations on the way forward. The data from OECD confirm that the rate of poverty of persons with disabilities has been higher by ten percentage points that that of persons without disabilities (approximately 23% compared to 13%) with very little variation between 2005 and 2019. The employment rates of persons with disabilities are stubbornly low with a gap of 40 percentage points, and annual wage salaries are also lower than those of persons without disabilities, which is partly linked to a skills mismatch. Social protection plays a key role in the prevention of poverty but needs to be better designed to ensure early intervention. Very important also is the strong argument that the way forward requires a much more rigorous disability mainstreaming in all relevant labor market measures, including vocational training and public employment services.

The contribution from Dorothy Nakato Mubezi, supported by the International Disability Alliance (IDA), focuses on the access to gainful employment for women and youth with psychosocial disabilities, an excellent example of intersectionality in action. Based on discussions with key informants, the contribution assesses the barriers and enablers faced by youth and women with psychosocial disabilities in Africa. Addressing discrimination and harassment, the provision of reasonable accommodations, as well as affirmative action are looked at both in the initial recruitment and in terms of career advancement. The contribution also includes very relevant recommendations to State Parties, to the private sector, and to organizations of persons with disabilities (OPDs).

John Stapleton provides an interesting in-depth analysis of the “welfareization” of disability benefits in Ontario over the last 10 years in a moment where a new bill is being introduced which seeks to end “welfareization” of disability benefits and effectively reduce poverty among persons with disabilities. The contribution provides an interesting view on how disability-specific benefits and mainstream social assistance benefits interact with each other, the latter increasing in significance and take-up, when access to the former has been tightened.

Doug Waxman’s contribution is based on the analysis of 130 studies that have looked at employers’ perceptions of persons with disabilities, usually based on self-reporting by employers. The self-reported positive attitude to persons with disabilities is however usually not consistent with the actual behavior in terms of employment of persons with disabilities. Mr. Waxman highlights that there is a gap in this type of analysis in the global south and provides a suggested way forward to better understand and assess the actual behavior of employers.

Blanck, Hyseni and Goodman’s chapter on economic inclusion and empowerment of people with disabilities discusses extreme disparities in economic inclusion. These disparities are heightened by and interrelated with other inequalities that marginalized populations experience such as higher rates of poverty and lack of access to education, housing, transportation, medical care, banking, and food. The COVID-19 pandemic has amplified the employment disparities between people with and without disabilities and within the non-monolithic disability community. The expansion of the gig economy, the non-traditional routes to employment, disability owned businesses, apprenticeships, and paid leave benefits may help.

Triggered by the five contributions, I would like to finish by highlighting several areas that, while often already receiving some attention, would benefit from further research and analysis to inform future policies:

- The challenges and opportunities of the future of work for persons with disabilities, including, among others, remote work, the gig, and platform economy.
- How to improve working conditions of informal workers with disabilities and how to eliminate barriers to their move to the formal economy.
- How to provide the required assistance and support to small- and medium-sized enterprises, so that they can contribute more to the employment opportunities of persons with disabilities.
- The possible use of behavioral science to bridge the gap between attitudes and actual behaviors.

Towards a Rights-Based Policy Environment for the Employment of Persons with Disabilities

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Gertrude Oforiwa Fefoame and Hannah Loryman

Contents

Abstract

Article 27 of the Convention on the Rights of Persons with Disabilities (CRPD) obligates States parties to recognize the right of persons with disabilities to work on an equal basis with others. The rights of persons with disabilities to work on an equal basis with others is also referenced in Articles 5, 8, 9 and 12, demonstrating the cross-cutting nature of employment as a policy issue. Effective

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implementation of Article 27 will also ensure that States parties meet their commitments under Sustainable Development Goal 8.5 on achieving the full and productive employment and decent work for all women and men, including persons with disabilities, and equal pay for work of equal value. The recent adoption by the Convention on the Rights of Persons with Disabilities (CRPD) of the General Comment on Work and Employment is a major step forward in clarifying the obligations of States parties regarding the right to work and employment. This chapter examines some of the key challenges arising for states parties in meeting their obligations under Article 27 and, in the context of the new General Comment, discusses the key factors required to create an enabling policy environment for the employment of people with disabilities, as well as key outstanding questions and gaps which will need to be addressed for successful implementation of the CRPD.

Keywords

Employment · Work · Convention · Disability · Policy

Introduction

Although data is lacking and comparisons across countries are challenging, it is widely recognized that persons with disabilities experience lower levels of employment than their peers without disabilities and that, when they do access employment, they are more likely to work part-time, for lower pay and in the informal sector (United Nations, 2018; Braithwaite & Mont, 2009; Mizunoya & Mitra, 2013). When in employment persons with disabilities are also more likely to face exploitation and discrimination (Galarneau & Radulescu, 2009, O'Hara, 2004). Women with disabilities are less likely than men to be in employment and face barriers as a result of discrimination based on gender, disability, and intersecting identities. Access to employment is also highly variable across impairment groups, with persons with intellectual disabilities consistently experiencing lower levels of employment and people with some impairments facing specific barriers – such as specific forms of discriminatory legislation against persons with psychosocial disabilities (Shaw et al., 2012).

Article 27 of the Convention on the Rights of Persons with Disabilities (OHCHR, 2006) obligates States parties to recognize the right of persons with disabilities to work on an equal basis with others. The cross-cutting nature of employment as a rights and policy issue is also demonstrated by the inclusion of references in Articles 5, 8, 9, and 12.

Effective implementation of Article 27 will also support States parties to meet their commitments under Agenda 2030, specifically Sustainable Development Goal 8.5, on achieving the full and productive employment and decent work for all women and men, including persons with disabilities, and equal pay for work of equal value but is also key to achievement of the Agenda more broadly (United Nations, 2015).

The recent adoption by the Committee on the Rights of Persons with Disabilities of the General Comment on the right of persons with disabilities to work and employment (OHCHR, 2022) is an important step forward in clarifying the obligations on States parties regarding the right to work and employment and, as such, marks an important point to reflect on some of the policy challenges that remain in realizing the Convention, and how the General Comment provides an important framework and direction of travel in overcoming these.

This chapter examines some of the key challenges arising for states parties in meeting their obligations under Article 27 and, in the context of the new General Comment, discusses the key factors required to create an enabling policy environment for the employment of persons with disabilities, as well as key outstanding questions and gaps which will need to be addressed for successful implementation of the CRPD. It does not intend to provide a comprehensive overview of the General Comment, but instead presents some key areas for discussion and reflection.

The CRPD and Employment of Persons with Disabilities

The right to work is a fundamental human right, and forms an inseparable and inherent part of human dignity, recognized and articulated across multiple human rights and legal instruments including The Universal Declaration of Human Rights (United Nations, 1948) and Articles 6, 7, and 8 of the International Covenant of Economic, Social and Cultural Rights (United Nations, 1966). The right to work and employment for persons with disabilities, as well as being enshrined in the CRPD, is also articulated in other key rights documents such as ILO Convention 159 (ILO, 1983).

Article 27 of the CRPD requires States parties to recognize the right of persons with disabilities to work on an equal basis with others, including their right to gain a living by work freely chosen or accepted in a labor market and work environment that is open, inclusive, and accessible. Article 27 sets out measures through which States parties can respect, protect, and promote the right of persons with disabilities to work and employment.

While the obligations of the CRPD sits with States parties as signatories, most rights require a multistakeholder approach if they are to be realized in practice. This is evident for the right to work, where a significant amount of employment will be within the private sector. Article 27 of the Convention requires states to place obligations on private sector employers, for example in the provision of accessibility and reasonable accommodation, whilst requiring States parties to adopt positive measures to promote the employment of persons with disabilities.

The equal employment of persons with disabilities cannot be achieved through measures that solely focus on employment. This is well recognized in the CRPD with references to work and employment also included across other Articles 8 on Awareness Raising, 9 on Accessibility, and 26 on Habilitation and Rehabilitation. The right to work can also an important enabler for the achievement of other rights, such as the Right to Health and Participation in Public and Political life.

It is important to be cognizant that while the engrained perception that many persons with disabilities cannot work does not hold true, it is also critical that discussions about the right to work for persons with disabilities do not cause the small minority of persons with disabilities that, even with the right accessibly environments and support, cannot work further violations of their rights. Comprehensive social protection floors (ILO, 2012) are an enabler to the right to work, but they also play a critical role in supporting those who either temporarily or permanently are unable to work (OHCHR, 2015).

Challenges in Implementing Article 27

The Committee's Concluding Observations[1] on Article 27 provide a useful entry point for understanding some of the policy challenges and areas of contestation that exist in securing the right to employment for persons with disabilities. Consistently the Committee highlights concerns about the low numbers of persons with disabilities in employment, particularly women and persons with intellectual or psychosocial disabilities and other contextually marginalized populations. As highlighted above, this holds across high-, middle-, and low-income countries in the employment data that exists.

Beyond this, the Committee's Conclusion Observations also make clear that there are similarities in challenges that States face in implementing the Convention.

The existence of a strong legal and policy framework for employment remains a significant challenge in many countries (United Nations High Commissioner for Human Rights 2021). The Committee has identified persistent gaps in policy and legal processes and frameworks as well as consistently raising the issue of non-implementation of laws and policies relating to employment. People with disabilities are also more likely to work in the informal sector, presenting additional and specific challenges for the development of an enabling legal and policy environment.

Reasonable accommodation is a foundational principle in the CRPD and is clearly linked to the equal realization of rights (Lawson, 2017). In relation to work and employment, the CRPD sets out that States parties should "ensure that reasonable accommodation[2] is provided to persons with disabilities in the workplace" (OHCHR, 2006). Reasonable accommodation, in tandem with accessible workplaces, plays a critical role in ensuring that persons with disabilities can realize their right to employment. Despite its importance, the Concluding Observations for the majority of States parties highlight issues and challenges with the provision of

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[1] The 17 Concluding Observations between 2019 and 2022 accessed on 3/9/22.

[2] Defined in the CRPD as: "necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms."

reasonable accommodation. The concept of reasonable accommodation will likely always contain some element of contestation, partly because the definition of "reasonable" will always be context-specific and require an element of judgment in delivery. However, clear definitions and robust guidance for implementation can and should eliminate some of this ambiguity. The Committee has identified a range of issues in providing reasonable accommodation; these include issues around the existence of sufficient legislation and policy, lack of implementation of legislation and policy, and lack of accountability and measurement.

Another consistent area raised by the Committee is the right of persons with disabilities to participate in the open labor market. Concerns expressed by the Committee demonstrate and emphasize the importance of the "right to work" not just being about the right to employment but the importance of the concept of "freely and openly chosen" for persons with disabilities (OHCHR, 2006). Legislation and policy which permits, and in some cases encourages, employment in "non-open" settings, is often seen as a legitimate part of a response to low employment levels by States parties. While this may seem like a pragmatic approach to address low numbers of people with disabilities in employment it is problematic on multiple counts. This includes concerns raised by the Committee that sheltered employment does not only violate people's right to work on an equal basis with others, but it can also lead to other rights violations, such as being paid below minimum wage.

General Comment on the Rights of Persons with Disabilities to Work and Employment

All treaties are written at a point in time and are a process of complex negotiations, discussions, and have to condense complex rights into short statements, which are therefore inevitably open to interpretation and reinterpretation. General Comments, therefore, provide an important and more practical interpretation of the rights, providing practical guidance to states to support implementation. They play a critical role in articulating the specific actions needed to realize the rights set out.

Human rights Committees, in developing General Comments, have to navigate a complicated path between protecting and promoting the rights of their constituency, expressing up-to-date expertise in an area, and keeping to the intent of their treaty, which has been ratified by States parties. The complexity of this can be partially understood by reading the submissions.

Although General Comments are not legally binding instruments, they provide "authoritative guidance" around implementation of the legally binding articles of a convention (OHCHR (n.d.). In September 2022, the Committee on the Rights of Persons with Disabilities published its eighth General Comment on Article 27. The development of the General Comment generated significant interest from States and those across the disability sector, with around 90 submissions made to the Committee in one round of input requested on the draft General Comment.

Key Aspects of the General Comment

Policy, Assumptions, and Value Systems

Policy decisions are rarely neutral and are a reflection of the values and assumptions that society and, by extension, policymakers hold. The CRPD is widely recognized as representing a paradigm shift from conceptualizing persons with disabilities as objects of charity to subjects with rights (Harpur, 2012). However, outdated modes of understanding disability still prevail in society and, as a result, in policy. This issue was brought to the forefront during the Covid-19 pandemic where government's responses to the pandemic demonstrated how entrenched discrimination often is Quinn (2000). In General Comment 8 the CRPD Committee explicitly names "ableism" as the underpinning values system, which drives medical and charity models of disability and, in turn, underpins much discrimination on the basis of disability.

While ableism is not a new concept and is widely used in academic literature, by activists and in some policy areas, it has not been used extensively in General Comments previously.[3] Making the concept of ableism explicit in relation to employment, and by extension other rights in the CRPD, is a helpful framing for unpacking the underlying drivers which have led to some of the policy decisions that are consistently raised by the Committee as undermining the rights of persons with disabilities in employment.

In particular, while ableism underpins many of the explicit forms of discrimination persons with disabilities experience in employment, the concept of ableism is particularly useful to understand some of the approaches and policies which are put in place by States in order to attempt to address the lack of inclusion of persons with disabilities in the labor market, but actually can be understood to be undermining the rights of persons with disabilities. This is notable around sheltered and segregated work, but can also be seen in the design of some affirmative action policies. Discrimination that is built into legislation, for example legislation that permits persons with disabilities being able to receive a lower than minimum wage, is also fundamentally built upon ableism.

This new emphasis on ableism is particularly pertinent as it gets to the core of the approach taken in the CRPD and its focus on not just addressing the outcomes of disability discrimination and rights violations, but also addressing the core reasons behind these.

Complexity of Policy and Legal Reform

It is increasingly common rhetoric within the disability sector that the policies and laws are in place around disability, but that they "just" need to be implemented.

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[3] General comment No. 5 (2017) on living independently and being included in the community briefly mentions ableism but does not expand on it in the way that this General Comment does.

Putting aside the complexities of implementation, which apply to the issues discussed throughout this chapter, this also oversimplifies what is needed in terms of an enabling policy and legal framework if the rights of persons with disabilities are to be realized in employment.

While there has undoubtedly been an increase in the existence of laws and policies on disability there still remains significant gaps. A recent study of all 193 UN member states which found that only 62% of countries prohibit disability discrimination in employment but that added to this only 33%, prohibit indirect discrimination (Heymann et al., 2022). Further studies have also highlighted the lack of legal and policy protection of women with disabilities (Braunmiller & Dry, 2022) and persons with psychosocial disabilities (Ebuenyi et al. 2019).

Another challenge links to the persistence of certain assumptions and value systems, as set out above, and how they persist within policy and legislation. For example, recent research in South America found that although all countries in the study had enacted legislation on the employment of persons with disabilities, all but one seemed to take a medical model and therefore perpetuated the association between disability and incapacity to work (Pinilla-Roncancio & Rodríguez Caicedo, 2022).

This demonstrates the critical importance of taking a holistic view of what the policy framework for the inclusion of persons with disabilities in the labor market should look like. The CRPD already clearly sets out some legislative and policy requirements of States parties through its General Obligations, and these apply to the right to work and employment. The General Comment sets out that States should introduce a national employment strategy and plan for action and also brings to the forefront a range of legal and policy provisions that are required to create an enabling environment for the employment of persons with disabilities. This is important ensuring that a comprehensive policy framework is in place.

The General Comment also emphasizes the need for effective redress mechanisms, without this accountability the existence of policies and legislation cannot be effectively implemented.

Affirmative Action

Affirmative action is one of the most commonly used policy instruments implemented by states to promote the employment of persons with disabilities. Although much broader, affirmative action is often seen in the form of quotas, and despite being frequently used across contexts, the effectiveness of quotas remain extremely contested. Quota systems, which usually take some form of requiring employers to hire a certain percentage of persons with disabilities, have been adopted by around 100 countries (United Nations, 2018; ILO, 2018).

Quotas vary significantly in how they are established and have often not been well evaluated or their impact understood. Many of the submissions made to the Committee when the General Comment was being developed expressed concerns about quotas. These concerns identified that quotas can risk perpetuating long held assumptions about the ability of persons with disabilities to work on an equal basis with others. They can reinforce the charity model of disability that the CRPD has worked so hard to remove. They may lead to employers hiring persons with disabilities, but in low-paid, low-progression jobs which can further entrench discrimination and exclusion. In other cases, quotas are not implemented and not enforced. Inclusion International highlighted that quotas “do not work for persons with intellectual disabilities” (Inclusion International, 2022). Susan Scott Parker in her keynote speech to the Committee stated that quotas, and their failure to increase employment “reinforces those same negative assumptions regarding ‘disability’ which caused them to come into being” (Scott Parker, 2021).

While there are strong opponents to quotas, as seen above, most do not argue for a removal of quotas but for modifications that address some of the challenges identified and lead to more effective implementation. As the ILO has identified, more recently quotas are being introduced in tandem with anti-discrimination legislation (ILO, 2018). Critically, the General Comment makes clear that quotas and other affirmative actions will not work if they are introduced in isolation, that where they are put in place they should form “part of a holistic approach.” Part of this holistic approach must be the existence a strong legislative and policy framework around discrimination. Non-discrimination laws will not alone address exclusion, but they provide an important basis upon which other policy responses can be built (Heymann et al., 2022).

The General Comment is important in that it provides a set of measures that should underpin affirmative action measures, including quotas, if they are to be considered in line with the CRPD. For example, as highlighted above, there is concerns that quotas may not work for all persons with disabilities and so the Committee highlights the importance of “incorporating a disability, gender and age perspective” in the General Comment. This will have to be a critical line of inquiry for the Committee going forward.

The Committee also highlights the need for greater assessment and evaluation of affirmative action policies and their implementation this will be critical to establish how best affirmative action can support the meaningful employment of persons with disabilities and avoid many of the pitfalls and challenges that are consistently raised and identified. In elaborating further on what affirmative action that is in line with the Convention looks like the General Comment provides an important framework upon which existing and new affirmative action policies should be assessed and developed. The Committee in its concluding observations often recommends that existing quotas should be implemented. While implementation remains a challenge, the elaboration made in the General Comment could also form the basis of recommendations by the Committee and support a more nuanced, evidence-based, approach to continuing to strengthen affirmative action.

While affirmative action goes beyond quotas, the dominance of quotas as an affirmative action measure remains clear and this is reflected in the input that the Committee received when preparing the General Comment, as well as in the Committee’s Concluding Observation. This may be a useful inflection point for the Committee, academia, and civil society to reflect on how to broaden discussions around affirmative action and ensure that a full range of affirmative action policies are being considered and developed by States parties.

Segregated Employment

As set out above, issues around segregated employment and lack of promotion of employment in the open labor market are often raised by the Committee in Concluding Observations.

The idea that persons with disabilities should be able to access employment in the open labor market is not new (or limited to persons with disabilities). Even prior to the development of the CRPD the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993) promoted access to the open labor market by persons with disabilities.

The CRPD itself emphasizes the employment of persons with disabilities in a labor market which is open but does not specifically mention segregated workplaces. The CRPD Committee has also previously articulated the link between quality inclusive education and employment in the open labor market through General Comment number four.

The General Comment therefore provides an important articulation of what it means for States parties to provide employment that is open. The General Comment clearly articulates that any form of segregated employment is not in line with the CRPD. The issue of segregated employment is identified by the Committee as one of the major and ongoing violations of the rights of persons with disabilities. States parties should now take steps to transition away from segregated employment. The issues around segregated employment are multiple. Segregation is both a practical problem, in that there is evidence that it restricts wages and career progression, for example, but the idea of setting up segregated employment as a response to the low employment of people with disabilities is fundamentally built on a charity model of disability which cannot understand that people with disabilities can work on an equal basis with others when the right conditions are in place.

The interpretation of the Convention on this issue is not without complexity. For example, Australia in its input to the General Comment makes the case that while persons with disabilities should not *only* be able to access employment in segregated settings the wording of the CRPD suggests that alternative forms of employment should not be prohibited, as long as they are not the only option (Government of Australia, 2022).

For some States parties segregated employment plays a significant part of their policy framework for attempting to increase the employment of persons with disabilities and therefore this transition will be complex. This is of course not to say that these States parties should not now transition away from segregated employment, but it is important to recognize that this transition may take some time. The General Comment recognizes this and so makes it clear that during this transition process segregated workplaces should be providing equal pay. In fact, ensuring that persons with disabilities received equal pay during this transition will be critical in starting to dismantle some of the pervasive norms and perceptions of the value of persons with disabilities' work that often underpin a model which favors segregated employment. The transition to a full open labor market must also ensure that it does not disadvantage those persons with disabilities who have always worked in segregated employment and therefore may not have had the opportunities to secure qualifications or skills which might be required in the open labor market.

The Role of Families and Discrimination by Association

As set out in the CRPD both persons with disabilities and their family members should receive protection and assistance to the extent to which "it enables families to contribute towards the full and equal employment of the rights of persons with disabilities" (OHCHR, 2006).

How the CRPD and its General Comments include families and caregivers of persons with disabilities remains an often-contested discussion for important reasons. The purpose of the CRPD is to protect and promote the rights of persons with disabilities themselves. Therefore, families and caregivers are not, and should not be, the priority of the CRPD. However, to ignore the important role that families and caregivers play in supporting some persons with disabilities to access their rights would be to ignore the reality for persons with disabilities.

Added to this, discrimination is often based on the negative stereotypes and attitudes that people hold about disability and, as such, families and caregivers can also experience discrimination because of their association with persons with disabilities, which can also have an impact on persons with disabilities. For example, a woman with a child with a disability might be assumed to be an unreliable employee and not given a position. This discrimination impacts on the woman herself, but it also impacts on her child. The discrimination in this case arises because of discrimination relating to the negative attitudes to disability, although it is directed at the person without a disability.

The General Comment therefore recognizes discrimination by association. This does not undermine the fact that persons with disabilities are the primary focus of the CRPD and does not deny the reality that discrimination and abuse of persons with disabilities often comes from those who are closest to them.

Informality

People with disabilities, and particularly women with disabilities, are disproportionately represented in the informal sector (Mizunoya & Mitra, 2013), where they will often have poorer job security, limited protections and limited access to accountability and redress mechanisms if they do experience discrimination.

Many of the issues discussed in relation to formal employment are also applicable to informal employment, but the responses required may be different and are often poorly understood.

The General Comment recognizes the need for states to respond to informality in employment in three ways: by protecting and supporting people in the informal economy, promoting and accelerating the transition to the formal economy, and preventing work in the formal economy from becoming informal. At the core of these responses is the need to reduce discrimination, through policy and legislation and behavior change among other mechanisms.

It is critical that protecting those in the informal economy is considered in the design, implementation, and accountability of policies around employment. The Committee has an important role in monitoring the implementation of the Convention in ensuring that in working towards the right to work and employment states are considering both formal and informal sectors.

Looking Forward: Emerging and Interconnected Issues and the Right to Employment

The Changing World of Work

In many places the nature of work is changing and will continue to change (World Bank, 2019). The General Comment recognizes that States must ensure that they respect, protect and promote the rights of persons with disabilities as these shifts occur and highlights specific areas such as the gig and platform economies and the transition to a green economy. Many of these changes will also interact with issues around informality.

The General Comment provides a framework for implementation of Article 27 across very different labor markets and contexts globally, and so it is also important to recognize that these shifting dynamics in work and employment will likely raise new concerns and issues for States parties. While these changes do not alter the rights that the CRPD provides, they may see new manifestations of existing discriminations and also present new opportunities for inclusion.

States, the Committee and civil society must continue to develop their understanding of how employment and labor markets are changing and the potential risks that this holds for persons with disabilities and their right to employment.[4] States parties and other relevant stakeholders should also be cognizant of the opportunities, changes in the labor market hold, and maximize the inclusion of persons with disabilities.

Unpaid Care

As highlighted, the Committee have repeatedly emphasized that women with disabilities face disproportionate barriers to realizing the right to work and employment.

The Covid-19 pandemic has brought to the forefront the recognition of the importance of, and lack of attention paid to, unpaid care as a rights and development

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[4] Some research is beginning to emerge in these areas, see for example Harpur and Blanck (2020) but this is still limited and largely in high-income settings.

issue.[5] Unpaid care and employment are intrinsically linked, with policies around care impacting significantly on people's, particularly women's, employment (Charmes, 2019). The disproportionate impact of unpaid care is one barrier to equal access to employment for women, with social and gendered norms and assumptions that women should play the main caregiving role significantly contributing to this (Sepulveda, 2013).

The ILO has included unpaid work in its definition of work (ILO, 2006) and the Sustainable Development Goals reflect unpaid care and domestic work in Goal 5 on gender equality. Although it is also notable that the indicators for the target require states to disaggregate by sex, age, and location, but not disability. In their contribution to the preparations for the General Comment Women Enabled International highlight that where "caregivers or care recipients are persons with disabilities, the opportunity costs of care work are often exacerbated" (Women Enabled International 2022). There is often little attention paid to disability within the dialogue around the impact on the unequal impact of unpaid care on women with disabilities, and if there is attention paid to disability it is by recognizing persons with disabilities as recipients but not also caregiver themselves.

Addressing the unequal impact of unpaid care on women, including women with disabilities, is critical if states are to achieve substantive equality. The General Comment specifies "unpaid work" as an arena where states parties should address exploitation, and highlights the need for affordable, accessible, and appropriate childcare. The General Comment therefore begins to make the link between employment and unpaid care for women with disabilities and provides a useful step forward which should be built upon by the Committee in monitoring the Convention and in future General Comments.

Social Protection

A full discussion of the importance of comprehensive social protection systems for persons with disabilities sat outside of the scope of this General Comment, although it was highlighted by contributors as a key consideration in realizing the right to employment. Social protection for persons with disabilities has often been tied to their "inability" to work (Devandas-Aguilar, 2015). The provision of social protection for persons with disabilities who are unable to work, be that temporarily or permanently, is a critically important element of any system. However, the dominance of this type of social protection can be argued to be linked to the underlying assumption that persons with disabilities cannot work, driven by ableism, and therefore the role of social protection is purely to "replace" income from employment. However, social protection should also play an enabling role in supporting persons with disabilities to access employment as well as covering the additional costs that persons with disabilities experience when participating in society on an

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[5] See, for example, the inclusion of care in the World Bank IDA's policy commitments.

equal basis with others. The General Comment makes an important statement in this regard by setting out that persons with disabilities should "not lose the benefit of disability allowances when they start work."

Conclusion

The General Comment on work and employment is a useful point for States parties, civil society, and other stakeholders to reflect on what is needed to ensure that the right to work and employment is achieved for persons with disabilities.

For States parties it provides critical guidance on areas of complexity surrounding the right to work and employment and it advances understanding on how to realize the right to employment.

The General Comment clearly articulates that the right to employment for persons with disabilities will not be achieved through one approach alone and States parties must adopt holistic and comprehensive approaches. This includes a comprehensive and cross-sectoral policy framework that not only supports people to be employed in the formal sector, but that also breaks down barriers to achieving the right to work in the informal sector.

Substantive rights under the CRPD continue to be explained and articulated through the General Comment, and it also brings to the forefront newer or more contested areas that it will be important for States to address and for the Committee to monitor and raise through its ongoing review process.

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Aligning Employment Promotion with Poverty Prevention

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Silvia Garcia-Mandico and Christopher Prinz

Contents

Abstract

Improvements in labor market outcomes for persons with disabilities lag far behind aspirations, failing to address high poverty risks. Social protection and employment policies play a key role in breaking the link between disability and

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This document, as well as any data and map included herein, is without prejudice to the status of or sovereignty over any territory, to the delimitation of international frontiers and boundaries and to the name of any territory, city, or area.

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poverty. These policies, however, need to be carefully designed to promote sustainable employment for persons with disabilities and avoid creating poverty traps. This chapter argues that social protection and employment policies for persons with disabilities should be approached through systematic disability mainstreaming, meaning treating persons with disabilities within the mainstream systems and services provided to persons without disabilities, to avoid perpetuating difference and disadvantage, and holding mainstream institutions accountable for reaching persons with disabilities. Individualized, targeted approaches are key, but they are key for everyone who needs support, irrespective of where the need for support originates from.

This chapter consists of four parts: an introduction with selected key poverty and employment figures for persons with disabilities in OECD countries; a section on the poverty-preventing role of social protection; a section on employability, employment promotion, and poverty traps; and a policy conclusion with focus on the need for rigorous disability mainstreaming.

Keywords

Poverty · Social protection · Labor market · Skills · Mainstreaming

Introduction

People with disabilities face large poverty risks, making social protection critical in breaking the link between poverty and disability, by covering the additional costs of disability and promoting employment. However, a real change will require shaking up the existing system, and thinking about policy differently, through a rigorous mainstreaming of all policies.

- **The link between poverty, employment, and disability is inextricable, as disability is both a cause and consequence of higher poverty levels and lower employment rates**. The data are unequivocal: People with disability (PwD) face higher poverty risks than people without a disability (PwoD), in part because their employment rates remain stubbornly low.
- **Social protection is necessary to prevent PwD from falling into poverty**. Benefit adequacy considerations must take a holistic view of the benefits system, as many PwD depend on top-ups provided through social assistance or, more often, on social assistance payments altogether.
- **Policy efforts to promote the employment of PwD must be oriented toward preventing people from getting to a stage from which there is no sustainable return to work**. This can be supported by policies promoting the early identification of barriers to employment, giving a greater role to the stages preceding application to disability benefits, i.e., sickness insurance and unemployment insurance.

- **Closing the skills gap is a condition for closing the employment gap of PwD**, which starts with inclusive education. OECD countries need to make efforts in ensuring inclusive mainstream secondary schooling, including apprenticeships and vocational schools, and in promoting an inclusive transition to the labor market. Public Employment Services also have a great role to play in promoting the transition from school to the labor market and ensuring the continuous learning and upskilling of PwD.
- **Truly achieving a policy transformation that promotes the employment of PwD while ensuring their safety net requires a rigorous mainstreaming of all policies** – in education policy, labor market policy, and social protection policy. Mainstream systems should follow the principle of personalization and individualization of supports and be accountable for the inclusion of PwD, in line with the UN Convention on the Rights of Persons with Disabilities.

Poverty, Employment, and Disability

A Large Share of People with Disability Live in Poverty Across OECD Countries

On average across OECD countries, almost one in four PwD live in a household with an income level below the poverty line (60% of the median). Figure 1 shows that poverty of PwD has steadily increased, from 18% of households with PwD living in poverty in 2005 to 23% in 2019. When comparing the poverty rates of households with PwD to those without PwD, we note that both the level and trends are grimmer for PwD. In 2019, 13% of households without PwD lived in poverty, resulting in a disability poverty gap (calculated as the difference in poverty rates between PwD and PwoD) of 10 percentage points. This disability poverty gap has doubled since 2005 due to a deterioration in the relative income position of PwD. What are the reasons behind this strong and persistent link between poverty and disability? The following sections unravel some of the key elements of this discussion.

Intergenerational Transmission of Disadvantage Is Stronger for People with Disability

PwD are more often raised in vulnerable settings, and more likely to become (or remain) poor themselves, making the intergenerational transmission of disadvantage a real challenge for PwD. Table 1 below shows that PwD have a substantially higher probability than PwoD of having lived in households in a bad or very bad financial situation during their youth. Low parental income puts children and young people at a disadvantage by limiting the resources available to be invested in promoting their well-being and developing their human capital. The children of poor

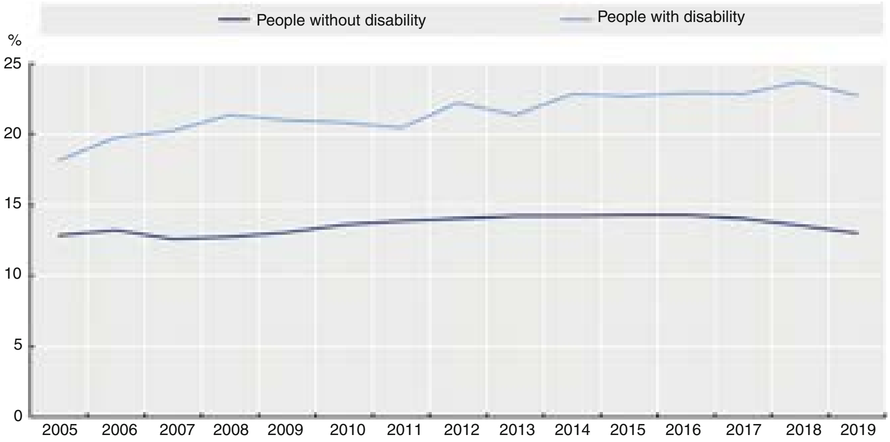

Fig. 1 The poverty rate of persons with and without disabilities across OECD countries.
Note: The data show relative income poverty, i.e., the share of people with and without disability living in a household with an income below 60% of the median income. Household income is equivalized for household composition by dividing by the square root of the size of the household. The data shows the unweighted average for a set of OECD countries, namely, Australia, Austria, Belgium, Canada, Chile, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Korea, Latvia, Lithuania, Luxembourg, Mexico, the Netherlands, Norway, Poland, Portugal, Slovakia, Slovenia, Spain, Sweden, Switzerland, the United Kingdom, and the United States. (Source: OECD calculations based on the European Union Statistics on Income and Living Conditions (EU-SILC, 2008–2019) for European countries. The Household, Income and Labour Dynamics in Australia Survey (HILDA, 2008–2017); the Canadian Income Survey (CIS, 2013–2019) provided by Employment and Social Development Canada; Chile's: Encuesta de Caracterizacion Socioeconomica Nacional (CASEN, 2016–2017); Mexico's Encuesta Nacional de Ingresos y Gastos de los Hogares (ENIGH, 2016); the Korean Labour & Income Panel Study (KLIPS, 2008–2018) and the United States Current Population Survey (CPS, 2008–2018))

parents are more likely to be poor adults than children that did not grow up in poverty (Bird, 2010). The fact that PwD are more often exposed to poverty when growing up than PwoD puts them at a higher risk of being poor when adults than PwoD. An additional factor, however, is that the strength of the intergenerational transmission of poverty may be stronger for PwD, especially for children with disabilities growing up in poor households. Children with disability have more health care needs and require more support to pursue education, and more time and resources to promote their well-being. In a context of financial and time deprivation, these needs may be more difficult to meet, resulting in lower development and a stronger transmission of poverty for children with disabilities than for children without disabilities (van der Mark et al., 2017). Table 1 can also be interpreted from another angle, by which disability is a consequence of poverty. Income and resources appear to affect health in early developmental stages (Cutler et al., 2011), which could affect adult health and the development of a disability. The additional costs related to having a household member with disability (either in terms of foregone work income and additional expenditures) can also cause financial hardship. Either way, poverty and disability are interlinked, which is a solid

Table 1 Intergenerational transmission of disadvantages hits people with disability harder. Parental and financial situation of respondents when aged 14, 2019

	People without disability (PWOD) (%)	People with disability (PWD) (%)	Difference (PWOD−PWD)
Living in a household with bad or very bad financial situation	8.98	16.61	−7.63***
Living in a household with moderate financial situation	54.31	55.02	−0.71**
Living in a household with good or very good financial situation	36.70	28.36	8.34***

Parental and financial situation of the respondent when aged 14. Respondents are aged 15 to 59 in 2019. Significance stars correspond to significance of a t-test of equal means between PWoD and PWD. *** p-value <0.01, ** p-value <0.05. Observations are 130,706 for PWoD, and 24,943 for PWD. Data represent 25 European countries: Austria, Belgium, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Latvia, Lithuania, Luxembourg, the Netherlands, Norway, Poland, Portugal, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, and United Kingdom

Source: OECD calculations based on the European Union Statistics on Income and Living Conditions (EU-SILC), 2019 Ad hoc module: "Intergenerational transmission of disadvantages, household composition and evolution of income"

argument for promoting disability-inclusive poverty reduction and (social) development strategies (World Bank, 2015).

Persons with Disabilities Face Stubbornly Low Employment Rates

PwD are not able to overcome the poverty-disability link by thriving in the labor market. PWD have stubbornly low employment rates, which is one of the key challenges of disability policy (OECD, 2010a, 2022b). Figure 2 below shows the employment rates of PwD and the gap in employment rates between PwD and PwoD on average across the OECD area. The crisis of 2008–2009 has affected employment rates of PwD and PwoD similarly (employment rates fell by 5.66% between 2008 and 2010, compared to 5.13% for PwoD). However, the recovery of PwoD has been faster, particularly in the past 3–4 years prior to the COVID-19 crisis. As a result, the disability employment gap has been widening over the past few years. More recent data suggests that the disability employment gap may have even further widened as a result of the COVID-19 crisis, at least for some countries (see the Office for National Statistics (2020) for the UK, and the Bureau of Labor Statistics (2022) for the USA). The postpandemic recovery for PwD, in the context of the current economic and inflationary shocks, are yet to be seen.

Limited improvements in employment rates of PwD and the unchanged disability employment gap are disappointing given the improvement over the past 15 years in the level of educational attainment of PwD (OECD, 2022b). This suggests that the necessary policy transformation that many countries have started over the past decade has not gone far enough, an aspect that will be discussed further below in this chapter.

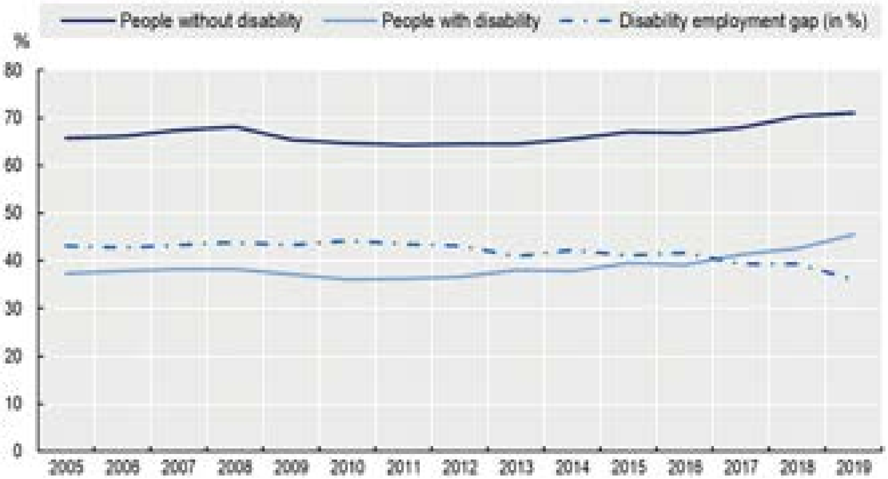

Fig. 2 Employment rate for people with disability and gap in the employment rate, calculated as the percentage point difference of rates of employment of people without disability and people with disability.
Note: data cover persons aged 15–69. The data shows the unweighted average for a set of OECD countries (see Fig. 1). (Source: OECD calculations based on European Union Statistics on Income and Living Conditions (EU-SILC, 2005–2019) for European countries; the Household, Income and Labour Dynamics in Australia Survey (HILDA, 2005–2017); Chile's Encuesta de Caracterizacion Socioeconomica Nacional (CASEN, 2006–2017); Mexico's Encuesta Nacional de Ingresos y Gastos de los Hogares (ENIGH, 2010–2016); the Korean Labour & Income Panel Study (KLIPS, 2008–2018) and the American Community Survey (ACS, 2008–2018). Data for Canada provided by Employment and Social Development Canada based on the Canadian Income Survey, 2013–2019)

A core reason behind the low employment rates of PwD is that it is harder for them to be hired and to stay in the labor market. Figure 3 below shows that, for European OECD countries, getting into the labor market is much more difficult for PwD than for PwoD (Panel A), and dropping out of the labor market is much more frequent for PwD than for PwoD (Panel B). Further disaggregation of these findings by demographic characteristics sheds further light on these labor market dynamics:

- Hiring rates drop sharply for older workers, which is true for PwoD as well. The disability gap in hiring rates is relatively small for both young workers (age 15–29) and older workers (age 50–69), with only a 2.5 percentage point difference on average (Panel A). However, the gap is very large for prime-age workers (age 30–49): In this age group, the annual hiring rate is only 10% for PwD but over 25% for PwoD. The disability gap in hiring rates increases with the level of educational attainment and is, on average, 1.5 times larger for men than for women.
- The labor market exit rate, i.e., transitions from employment to inactivity, is significantly larger for young and older workers, irrespective of their disability

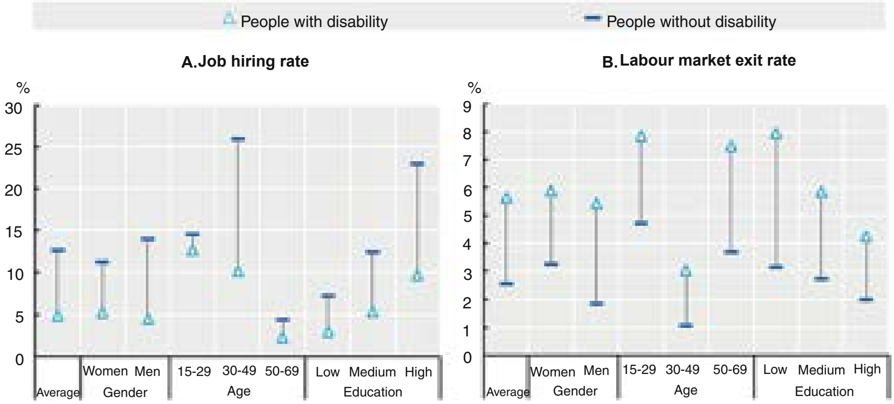

Fig. 3 Labor market transitions by disability status and demographic characteristics, average of 26 European OECD member countries, average over 2016–2019.
Note: Data show the unweighted average of the 25 European OECD countries as listed in Table 1. People with disabilities are defined as those who 1) declared to suffer from any chronic illness or condition and 2) with moderate to severe activity limitation due to health problems. Levels of education are defined according to the International Standard Classification of Education (ISCED), where low refers to below upper-secondary, medium to upper secondary, and high to tertiary education. Labor market transitions refer to individuals moving from one employment status to another in the year before the survey. Panel A: The job hiring rate is the share of those who are employed by the time of the survey but did not have a job the previous year, over the nonemployed. Panel B: The labor market exit rate is the share of those who were inactive at the time of the survey, but the previous year were employed, out of all the employed. (Source: OECD calculations based on European Union Statistics on Income and Living Conditions (EU-SILC, 2016–2019)

status. The likelihood of exiting the labor market is much higher for PwD in all sociodemographic groups, suggesting that many workers exit the labor market permanently due to health problems or disability (Panel A).

Persons with Disabilities Earn Lower Wages

PwD not only work less often than PwoD, but when they work, they tend to earn less. The average wage of PwD is about 85 to 87% of the average wage of PwoD (Fig. 4). There is substantial variation across countries. In some OECD countries, for instance, Korea, Mexico, the Baltic countries, Sweden, and Norway, the disability wage gap is (still) very large. In other countries, like Austria, Australia, and the Netherlands, PwD earn 90% or more of the wage of PwoD, and Greece and Italy appear not to have any disability wage gap. In the latter two countries, this is coupled with a very low employment rate among PwD; hence, selection effects seem to be at stake.

The disability wage gap can result from discrimination against PwD, due to stereotypes or preconceptions about PwD's productivity. Ameri et al. (2017) find that PwD face discrimination during the hiring process, as they are less likely to be called for an interview. This discrimination could also translate into lower pay.

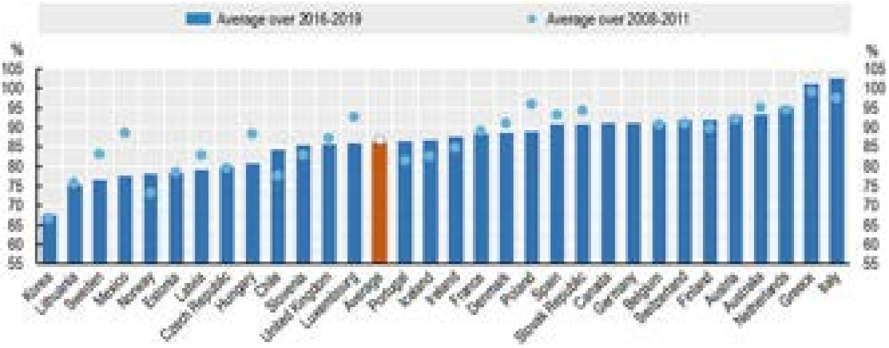

Fig. 4 Average annual full-time wage of people with disability over people without disability. Note: Data refer to annual employee wages employee cash or near cash income for employees and cash profits or losses from self-employment for persons self-employed (European countries); main labor income in cash (Chile); financial year gross wages and salary (Australia); average hourly wage excluding self-employed and the Canadian Armed Forces (Canada); total after-tax yearly earned income (Korea); main wage in main work, piece rates, commissions, payment for extra hours in main work, incentive pay, bonus, holiday pay and cash income second job (Mexico), and total wage and salary earnings (United States). The period 2016–2019 refers to 2012–2015 (Korea). The orange bar is the unweighted average of the countries shown excluding Canada and Germany which do not have data for the earlier period. (Source: OECD calculations based on European Union Statistics on Income and Living Conditions (EU-SILC, 2008–2019) for European countries. Exceptions: 2016–2018 (Belgium, Iceland, Ireland, Italy, and the United Kingdom). The Household, Income and Labour Dynamics in Australia Survey (HILDA, 2008–2017); the Canadian Income Survey (CIS, 2016–2019) provided by Employment and Social Development Canada; Chile's Encuesta de Caracterizacion Socioeconomica Nacional (CASEN, 2010–2017); Mexico's Encuesta Nacional de Ingresos y Gastos de los Hogares (ENIGH, 2016); the Korean Labour & Income Panel Study (KLIPS, 2008–2018), and the United States Current Population Survey (CPS, 2008–2018). Panel B: European Working Conditions Survey (EWCS)

Selection into different occupations and working arrangements can play a crucial role in explaining the disability wage gap. US Census Bureau research shows that PwD often work in certain low-paid occupations, and that among people working similar jobs and schedules, the median earnings for PwD are very close to the earnings for PwoD (Cheeseman Day & Taylor, 2019). Other research for the UK finds that the disability wage gap only halves when taking into account differences in characteristics, such as selection into low-paid occupations, part-time work, and a lack of high-level qualifications (Longhi, 2017). This indicates a substantial need for both policies to support the upskilling of PwD, and to address demand-side discrimination against PwD.

Adequate Social Protection: Breaking the Link Between Poverty and Disability

Social protection is essential in breaking the link between disability and poverty, particularly among those with severe disabilities who cannot work. By providing adequate social protection that prevents poverty, governments can support their citizens in making productive human capital and health investments, thus promoting their well-being and self-sufficiency (Hoynes et al., 2016; Brown et al., 2020). In the case of disability, social protection may also prevent the occurrence of extreme events: Deshpande, Gross, and Su (2021) show that receipt of disability allowances reduces the likelihood of bankruptcy, foreclosure, and home sale, which reflect reductions in financial distress. When well designed, social protection can be a powerful, and necessary, tool to support PwD.

Most countries provide disability-specific social protection programs for PwD that are granted after a certification of disability or long-lasting health issue. These are disability benefits and pensions, but also sickness benefits, especially when these can be granted for a long time. When evaluating the social protection coverage of PwD, however, focusing only on these *health-related* benefits is likely to give a partial picture of the true extent of social protection use. For instance, some PwD are excluded from health-related benefits if they do not have sufficient social security contributions, leaving them to rely on social assistance and means-tested programs as their sole source of income. Even when eligibility is ensured, health-related benefits may be too low and social assistance may play a key role in supplementing disability payments. This creates a strong nexus between the contributory, *health-related*, benefits and the noncontributory, *assistential*, system when it comes to supporting PwD. More generally, it also means that it is crucial to keep a holistic view of the social protection system when assessing how well PwD are covered and supported by social protection.

Vulnerable Persons with Disabilities Are Well Covered by Social Protection

The coverage of social protection programs is good in most OECD countries, as most PWD not working are supported through at least one type of income-replacement benefit. On average across the OECD, 87% of PwD with severe disability and not working receive any benefit, ten percentage points less for those with a moderate disability (Fig. 5, Panel A). Differences across countries are fairly small, with only a handful of countries having a coverage below 80% for those people with severe disabilities and not working. The differences in coverage between people with moderate and severe disabilities are also similar across countries, ranging between 5 to 10 percentage points, except for Iceland and Italy.

Country differences appear much larger when looking at narrowly defined *health-related* benefits only, i.e., sickness and disability benefit programs. Across all OECD countries, one in two nonworking persons with severe disability and one in four with moderate disability receive a health-related benefit (Fig. 5, Panel B). Country differences range from only 20% for people with severe disability in France to almost 70% for persons with moderate disability in Norway. This reflects how the role of different working-age benefits varies across countries. In Nordic countries, disability and sickness benefits are generous and with lenient eligibility criteria, while in other countries social assistance plays a greater role.

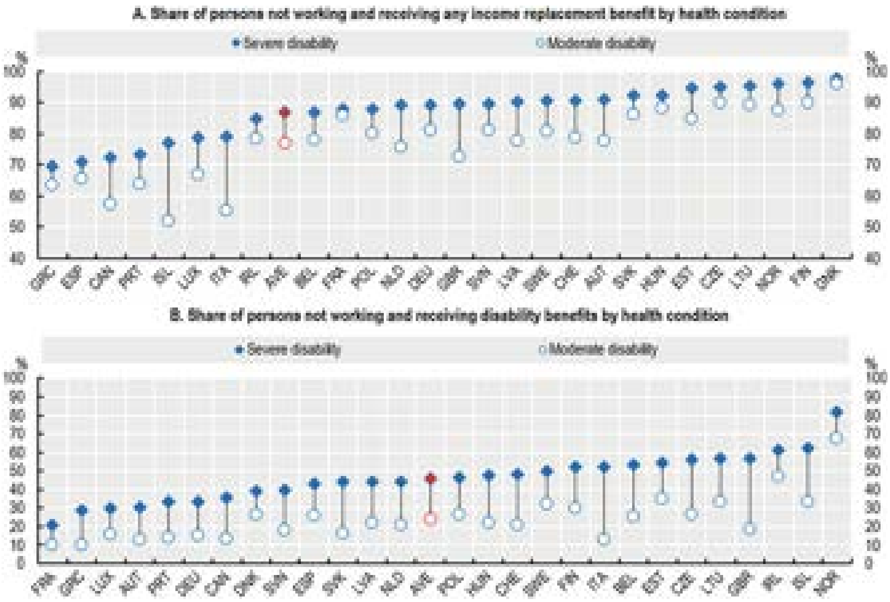

Fig. 5 Share of persons not working and receiving income replacement benefits by health condition.

Note: Any income replacement benefits include disability, sickness, unemployment, old age, and social assistance benefits. For Canada, any income replacement benefits include health-related or unemployment or old age or social assistance and refer to 2017. The purple markers (AVE) represent the unweighted average of the 26 countries shown. Data are not available in 2019 (Belgium, Ireland, Iceland, Italy, and United Kingdom) and 2018 (Estonia). (Source: Data provided by Employment and Social Development Canada based on the Canadian Survey on Disability, 2017, and European Union Statistics on Income and Living Conditions (EU-SILC, 2016–2019))

These charts show that, in many countries, PwD are frequently supported through social assistance, i.e., a mainstream program, rather than disability or health-specific benefits. This raises a more general question: **Can PWD be covered through mainstream programs (such as social assistance benefits), or are they better off when covered through specific programs (such as disability programs)**? To answer this question, the following section looks at the poverty-alleviating effects of social assistance and health benefits.

The Poverty Reduction of Social Protection Is Not Very Large Despite the Broad Coverage

Beyond social protection coverage, it is also crucial to look at its poverty-prevention role. To do so, one can look at how poverty would look like for PwD would there be no social transfers. Figure 6 shows that across European OECD countries, social protection prevents almost 50% of persons with disabilities from falling into poverty.

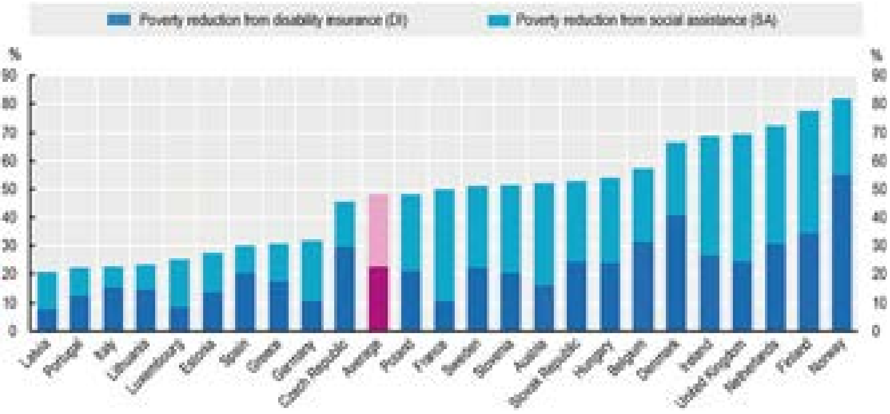

Fig. 6 Change in poverty headcount pre- and postsocial transfers, 2019.
Note: Poverty headcount among persons with disabilities is defined using 60% of median-equivalized income as poverty line. All poverty reductions are calculated as the actual poverty headcount minus the hypothetical poverty headcount resulting using a pretransfer (DI, SA, or SP) share of income. Pretransfer income is calculated following Ravaillon (2008). This approach assumes that in the absence of social insurance, individuals will self-insure (work more, intrahousehold substitution, etc.), but only partially compared to social insurance. For social assistance, it assumes two behavioral responses: (1) Pre-DI income is measured by subtracting to the equivalized income 50% of the equivalized income from disability benefits; (2) pre-SA income is measured by subtracting to the equivalized income 100% of the equivalized income from social assistance. SA includes cash-based means-tested programs (e.g., social assistance, child support, and any other social exclusion program). The purple bar represents the unweighted average of the countries shown. (Source: OECD calculations based on the European Union Statistics on Income and Living Conditions (EU-SILC))

Seen differently, however, this means that **more than 50% of PwD fall into poverty despite the coverage of social protection**, meaning that there is still a long way to go in eradicating poverty through social protection. Disaggregating this result by type of benefit lifting PwD out of poverty reveals substantial differences across countries. Social assistance has a greater impact on the poverty reduction of PwD than disability benefits in countries where disability insurance has strict eligibility conditions (e.g., Austria), or where disability benefits are low and often topped up by means-tested support (e.g., the UK). Instead, in Mediterranean countries (where take-up of social assistance is low) and most Nordic countries (where disability benefits are generous), disability benefits have a greater poverty-alleviating effect than social assistance.

Extra Costs of Disability May Not Be Well Accounted for in Social Protection Programs

How is it that despite the substantial coverage of PwD in social protection programs their poverty-alleviating role remains limited? A potential argument is that benefits may be too low for PwD, which makes it crucial to think about **PwD's extra direct and indirect costs of disability**. Direct costs refer to additional expenditures caused by a disability, i.e., higher costs for PWD and their families to access essential services or achieve social and economic participation. Indirect costs refer to foregone income due to limited access to education and barriers to gaining and retaining employment, as well as the foregone income for family members that give up school or work opportunities to provide support (Mont & Cote, 2020). Indirect costs may be captured in Fig. 6, where there is still a long way to go to eliminate PwD's poverty through social protection as PwD are not adequately supported through mainstream social protection, and are often excluded from disability benefits. Direct costs instead imply that the poverty level of PwD is underestimated when using standard poverty thresholds, as PwD will often have a higher level of consumption to maintain the same standard of living as PwoD.

The literature has relied on several **strategies for measuring the additional direct costs of disability** (see (Mont & Cote, 2020) for an in-depth review):

- **Goods and services used**. This approach surveys PwD to ask how much they have spent on goods and services necessitated by their condition. While straightforward, this strategy does not capture what the real costs for equal participation are, as it provides a measure of what is spent, which could be different to what is needed.
- **Goods and services required**. This method expands on the goods and services used approach by asking PwD what expenditures would be needed for equal participation, thus trying to approximate the realized and necessary additional expenditures of disability. This method however can be misleading, as it runs the risk of underestimating the costs, especially if PwD are not fully aware of what goods and services could potentially be available to them or could support them in equal participation.
- **Standard of living (SOL)**. This approach approximates the costs of disability by looking at the additional income needed for a household with PwD to achieve the same SOL as a household without PwD of similar characteristics. The main challenge of this approach is to measure a SOL. Zaidi and Burchardt (2005) propose three SOL indicators: (1) whether the household has any savings; (2) an index of possession of consumer durables; and (3) a subjective assessment of the household's financial situation. The SOL approach, with various SOL definitions, is frequently used as it can be implemented with most expenditure or living standards surveys, as long as they have questions identifying PwD.

Mitra et al. (2017) summarize the results of 20 studies evaluating the additional costs of disability using the three methods explained above. Estimated costs have a wide range, but most studies fall between the range of one-third to two-thirds of the average income, confirming the substantial direct costs of disability. These results need to be qualified by the severity of disability: persons with severe disabilities have costs of disability 30 to 50% higher than those with moderate disabilities, particularly on health-related expenditures, assistance with daily needs, and transportation costs (Zaidi & Burchardt, 2005; Cullinan et al., 2011; Vu et al., 2020). Higher costs are also estimated for PwD living alone or in small households, potentially explained by a more limited informal caregiving (Mitra et al., 2017). This means, however, that these costs could be indirect in larger households, as family members forego formal employment to give informal care. Morris and Zaidi (2020) evaluate how the poverty measurement of PwD changes when accounting for the additional costs of disability on a sample of older working-age adults. They find that on average across European countries, poverty among PwD doubles when considering the extra direct costs of disability.

Disability-Inclusive Social Protection Must Account for the Extra Costs of Disability

In line with the evidence of substantial additional costs of disability and its impact on perceived poverty, **how can mainstream social protection be designed to be inclusive to PwD by accounting for the extra costs of disability?** One first approach is to adapt means-tests to poverty lines that represent PwD, under the assumption that PwD require a higher income than PwoD to live out of poverty. Mont and Cote (2020) propose setting higher means-tested levels for PwD, to incorporate the additional income used for disability-related expenditures. Foregone income in the household should also be taken into account, as this could represent additional expenditures in care. A second approach is to set the right level of social assistance benefits by ensuring a guaranteed standard of living rather than a guaranteed minimum income. This means increasing the minimum level of benefits for PwD, for example, using equivalence scales that would give a higher weight to a PwD within a household, and calculating benefits accordingly (Mont & Cote, 2020). Another approach, which is implemented in many OECD countries, is to provide separate programs that cover the extra costs of disability. These programs can take the form of additional cash to cover disability-related costs (such as the attendance allowance in the UK), or in-kind benefits (Zantomio, 2013).

One approach to effectively support PwD would be to consider a more unified system of income support provisions for out-of-work individuals. As presented by MacDonald, Prinz, and Immervoll (2020), such a system could take the form of a (single) benefit to compensate for the loss of earnings and tailored extra support to respond to individual circumstances, including covering the extra costs of disability. Designing such an approach, which effectively aims at addressing the fragmentation of social protection through its mainstreaming, fits into the much broader debate on how to design social protection optimally. What role should social insurance have, compared to social assistance? The rising numbers of nonstandard workers pose a problem for traditional contributive social insurance, as just as with many PwD, they do not fit into the framework of social insurance (OECD, 2018). The need to make social protection future ready has brought the idea of a universal basic income back to the center of the debate (Gentilini et al., 2020). One argument frequently used against universal basic income is that there is limited empirical evidence on how such a program could look and be delivered. However, the increasing role that social assistance is playing is bringing most social protection programs to a state which is, conceptually, not too far away from that of a single working-age payment, but with numerous inequalities and poverty traps. This is particularly so for PwD, as social assistance in most countries is not disability inclusive and does not cater to the needs of PwD. Thinking about how to design social protection for all should thus be a priority among governments.

Employment Promotion: The Key to Preventing Poverty Traps

Providing social protection is key to preventing PwD from falling into poverty, by allowing them to cover the direct and indirect costs of disability and breaking the liquidity constraints that would prevent them from making investments toward self-sufficiency. However, as the vast majority of PwD receive disability benefits and other benefit income, often for most of their adult lives, it is a well-studied fact that social protection income may crowd out work income (Autor & Duggan, 2006). This is worrying, as the longer people rely on benefits without working, the more their skills depreciate and distance to the labor market increases, making it increasingly difficult to return to work. This generates a self-reinforcing mechanism, which can make PwD fall into poverty traps. To break the link between poverty and disability in a sustainable way, it is key to promote the employment of PwD. Governments may do so by designing social protection programs that focus on early intervention as a tool to promote the employment of PwD, and by ensuring that they have the skills to thrive in the labor market.

Designing Social Protection for Early Intervention

To promote the employment of PwD, policymakers should design disability benefit systems and, more generally, **social protection policies that aim at identifying barriers to work early and intervening quickly**. Early identification of barriers to employment requires giving a great role to the stages preceding application to disability benefits, in particular, during sickness benefit programs. Efforts made in the first months of sickness absence are crucial, as a return to work is very unlikely after a period of sickness absence of 5–6 months (OECD, 2015). One of the key elements to a successful return-to-work during sick leave is to secure the **strong involvement of employers** by introducing the right incentives to support a return to work (OECD, 2022a). Employer involvement can take the form of giving them a participating role in funding sick-leave compensation. The Dutch Gatekeeper protocol is a successful example of such a policy, by requiring employers and employees to draft a return-to-work plan, and the employer to finance sick pay for up to 2 years (Koning and Lindeboom, 2015). Employers' involvement can also be ensured through the promotion of graded return-to-work, which is shown to promote full return-to-work, at least in the short term (Meneses-Echavez et al., 2018; Kools &

Koning, 2019). Another key element to a successful early intervention is to **setting limits to the sickness scheme**, for instance, by capping the duration of sickness schemes, keeping a close monitoring of sick-listed individuals by regularly reassessing them, and avoiding overly generous sickness insurance programs (De Jong & Van Der Klaauw, 2011; Hägglund, 2013). Lastly, **return-to-work strategies should be flexible**, focusing initially on supporting a return to the previous employer, but expanding the support to the entire labor market as soon as a return to that employer is unviable (OECD, 2022a) and (OECD, 2022b). This expansion to the entire labor market requires a fluid cooperation with the Public Employment Services (PES).

A substantial share of PwD enters disability programs through the unemployment or social assistance system. Disability claimants not following the standard pathway of sickness insurance may fall between the cracks of standard early intervention measures, which gives a larger role to other institutions, such as the PES. Jobseekers must register with the PES in most OECD countries, which puts the institution in a good position to identify early barriers to employment among jobseekers and to support them. Once barriers to employment are identified, PES interventions should focus on finding new employment, with a strong focus on providing inclusive and personalized career guidance (OECD, 2022b). Participation in PES measures to find employment should not be automatically halted in the face of health issues or disability but rather should complement health rehabilitation (OECD, 2022a). This requires a strong cooperation between the PES and the health sector, which in most countries is insufficient.

Tackling the Skills Mismatch of Persons with Disabilities

PwD can only fill a vacancy or keep a job if they have the required skills and upgrade those skills in a constantly changing labor market. Yet, data suggest that the skills disadvantage of PwD is large, which makes **closing the skills gap is a condition for closing the employment gap of PwD**. Figure 7 shows the share of low literacy and numeracy skills among selected groups extracted from the PIAAC survey. Almost 50% of those with a permanent disability have low literacy skills and 55% have low numeracy skills. This compares to just over 20% and 25%, respectively, for the total population; 30% and 35%, respectively, for older workers; and 40% and 45%, respectively, for the low-educated population. Is it important to note that the PIAAC data only include information on persons with permanent disabilities, e.g., those who say that “permanently disabled” best describes their current labor market situation. This group likely contains those with more severe disabilities who are furthest away from the labor market. This substantial skills gap should therefore be seen as an upper bound estimate of the share of those with disabilities with low skills.

The education and skills gap start very early in life (OECD, 2022b), and so policies should first focus on **providing inclusive education to all**. Countries have made considerable efforts toward inclusive education systems: first, through the

Fig. 7 Share of low literacy and numeracy skills aged 15–69 among selected groups, OECD average, 2019.
Note: See https://www.oecd.org/skills/piaac/Key%20facts%20about%20the%20Survey%20of%20Adult%20Skills.pdf for definition of low skills. With permanent disability: "permanently disabled" best describes their current labor market situation. Older: aged 55–65. Low-educated: below upper secondary education. Data for Belgium refer to Flanders. OECD is an unweighted average and excludes countries not participating in PIAAC (Colombia, Costa Rica, Iceland, Latvia, Luxembourg, Portugal, and Switzerland) and countries with low number of observations (Australia, Japan, Sweden, and Tûrkiye). (Source: OECD calculations based on the Survey of Adult Skills (PIAAC), https://www.oecd.org/skills/piaac/)

identification of special education needs, and second through the enrollment of young PwD in mainstream classes. Efforts should continue to achieve a greater inclusion of PwD in mainstream classes, not through disability labeling, but by implementing inclusive education principles, which rely on individualized educational planning and understanding the needs of every child. Inclusive schooling has become the norm in many countries at primary school age but not at higher levels of education. For many young PwD, the transition to mainstream secondary school, including vocational schools and apprenticeships, and correspondingly also mainstream tertiary education, is still difficult. To complete the transition toward inclusive education systems, countries need to focus on ensuring that secondary and tertiary education is also inclusive.

PES play a key role in supporting the transition from school to education, and in providing adult learning that makes up for lower levels of education and skills. Data show that few PwD that receive sickness and disability benefits participate in PES-provided adult learning (OECD, 2022b). A principal reason for this is that few PwD register with the PES. Increasing the number of persons on incapacity benefits who register with PES is an essential first step toward promoting adult learning rates among PwD. The second key step is to tackle the motivational barriers of PwD by making adult learning relevant for employment. To do so, PES should focus on providing programs that aim at improving basic skills, including digital skills, and that are practical, such as work-based learning.

Linking social protection to policies supporting the transition from school to education is crucial to support young people with disability, including those with congenital disabilities, thrive in the labor market. On its own, social protection for young people with disability may result in lower employment during adulthood, by giving rise to perverse incentives and a welfare culture. On the other hand, school-to-work supports and services alone are not sufficient for many young people with disability, as they do not provide the safety net necessary to enable investments in human capital for young people (OECD, 2022b).

Policy Discussion: A Need for Rigorous Mainstreaming

This chapter has illustrated not only the critical role of social protection in providing a safety net to PwD, but also its importance in promoting the employment of PwD when combined with early intervention and measures to close the disability skills gap. Over the past decades, countries have made considerable efforts to make disability programs more active and compatible with work, with a focus on early intervention during sickness insurance. Yet, PwD continue to face high poverty levels, largely because their work potential has not been unlocked. This suggests that the necessary policy transformation is incomplete and **resources invested in creating equal opportunities for PwD continue to be insufficient**:

- The share of rehabilitation and employment-related measures in total spending on incapacity across all OECD countries has barely changed from 9% in 2007 to 10% in 2017.
- The focus in policy has been on promoting employment efforts in disability benefit programs, not recognizing that people applying for a disability benefit will often have had fragile and interrupted employment experiences and may have been navigating the welfare system for years. Interventions should start early in life or as soon as any barriers to employment become visible.
- The skills gap has not been tackled sufficiently. Despite longer schooling and school completion at a higher average level, the education and skills gap has not closed, or not enough. This means that PwD are still less skilled than PwoD and thereby often less attractive to employers.

Truly achieving a policy transformation that promotes the employment of PwD while ensuring their safety net within existing systems and structures appears difficult. Current systems and structures tend to support PwD through special programs and measures, almost always requiring a disability certification, which in most cases delays intervention and creates difference between PwD and PwoD. In addition, current structures generate dualities in how PwD are supported: Some fall under the coverage of special programs, while others are covered by mainstream programs. Yet, current mainstream programs are not necessarily disability inclusive, generating unfairness within the group of PwD. The United Nations (UN) Convention on the Rights of Persons with Disabilities proposes a new thinking approach, by calling on

States parties to ensure that persons with disabilities receive equal access to mainstream social protection programs and services as well as access to specific programs and services for disability-related needs and expenses such as support services. More generally, there is a need to think about **how can all PwD be better supported through mainstream supports and institutions** – in education policy, labor market policy, and social protection policy.

A first key element of disability mainstreaming is the **personalization and individualization of supports**. Individualized, targeted approaches are key, but they are key for everyone who needs support, irrespective of where the need for support originates from. Policies should aim at actively understanding and reducing the impact of any barriers, including barriers and disabilities, within all mainstream systems.

A second element of disability mainstreaming is to ensure that **mainstream policies are accountable for disability inclusion**. Successful mainstreaming requires strong responsibilities for all stakeholders and institutions, including PwD themselves. It also relies on the application of the principle of full participation and equalization of opportunities for, by, and with people with disability (*Nothing about Us, Without Us*).

Disability mainstreaming will need to be different in the future and **expanded to all policies and services**. This is also important in view of the big ongoing shifts in the economy and labor market, which come with new risks and new opportunities. For PwD to benefit fully and equally, a mainstreaming approach should take into account the diversity of PwD, and be adopted through all areas of policy to avoid that future risks outweigh future opportunities.

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Access to Gainful Employment for Women and Youth with Psychosocial Disabilities in Africa: A Case Study

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Abstract

Persons with psychosocial disabilities face.

Introduction

Despite the fact that many African countries have signed and ratified the UN Convention on the Rights of Persons with Disabilities (CRPD)[1] and adopted the Sustainable Development Goals (SDGs),[2] yet employment of persons with psychosocial disabilities in Africa is perceived to be much lower when compared to the general population and when compared to the different categories of disabilities. Considering the aspirations of SDG8[3] read with Article 27 of the CRPD,[4] there are substantial barriers to the participation of persons with psychosocial disabilities that need to be addressed.

Heightened levels of exclusion are often faced by individuals with specific types of impairments, such as persons with psychosocial disabilities, as well as by those experiencing multiple discrimination due to the intersection of disability with other aspects of identity such as gender and age.[5] There is generally a lack of data on disability and employment but available evidence suggests that people with disabilities are more likely to be unemployed than their peers without disability, especially youth and women.[6]

Women and youth with psychosocial disabilities face several barriers in access to employment in the open labor market that include attitudinal barriers related to mental illness, lack of supports in case of crisis, social stigma and discrimination, and perceptions of persons with psychosocial disabilities as lazy, destructive, and unproductive (Ebuenyi et al., 2020). Other barriers include the lack of social support,

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[1] For example, Uganda signed and ratified the CRPD and its Optional Protocol on 25 September 2008 without any reservations. For others, see https://www.un.org/disabilities/documents/maps/enablemap.jpg

[2] Uganda was one of the first countries to develop its 2015/16–2019/20 national development plan in line with the SDGs. https://www.ug.undp.org/content/uganda/en/home/sustainable-development-goals.html

[3] https://sdgs.un.org/goals/goal8

[4] Article 27 https://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx#27

[5] Inclusion Works Uganda Situational Analysis June 2020 update https://opendocs.ids.ac.uk/opendocs/bitstream/handle/20.500.12413/15481/Uganda_IW_SITAN_June%202020_updated.pdf?sequence=5&isAllowed=y

[6] UN Department of Economic and Social Affairs Disability https://www.un.org/development/desa/disabilities/youth-with-disabilities.html

social protection measures to cover disability related extra costs that are compatible with work including health insurance and denial of reasonable accommodation at workplaces (Ebuenyi et al., 2019).

While many impairments are observable, and thus are generally accepted by employers as requiring accommodation on the job (e.g., in the form of assistive technology, duty modifications, and assistive devices), a psychosocial disability is not obvious. Persons with psychosocial disabilities are denied reasonable accommodation discussed in the proceeding chapter (for example, flexible working hours, short but frequent breaks, breaking down large projects into smaller achievable tasks, minimizing environmental stimuli – noise, lights, access to a resting place in the middle of a working day) in work places because there is generally a lack of clarity as to their reasonable accommodation needs (Holness, 2016), as stipulated in Article 2 of the CRPD establishing that denial of reasonable accommodation constitutes discrimination on the basis of disability.

As observed by the Stakeholder Group of Persons with Disabilities for Sustainable Development, “Multiple intersecting factors restrict persons with disabilities’ access to decent work and employment, including: inadequate laws and policies; discriminatory social norms and hiring practices; a lack of access to education and training; unequal access to resources, information, technology and networks; accessibility challenges; lack of reasonable accommodations in the workplace.”[7]

Many women with psychosocial disabilities live in poverty; given that many are unemployed, those who are employed work mostly in marginal, seasonal, and menial jobs.[8] Indeed, persons with psychosocial disabilities in Africa are vulnerable to situations of forced labor and exploitation due to prejudice related to the misconceptions around their “mental capacity.”[9] Africa has the world’s youngest population, and it is growing rapidly. The 2030 Agenda for Sustainable Development underscores the importance of promoting rights of young people and meeting their needs, in all their diversity.[10]

Existing vulnerabilities and discrimination also need to be considered especially in the context of the COVID-19 pandemic and its aftermath. The marginalization faced by persons with disabilities in social, economic, and health terms, as well as limited access to public services, will add to the threat to lives and livelihoods that the COVID-19 crisis poses.[11]

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[7] Stakeholder Group of Persons with Disabilities for Sustainable Development, “Ensuring inclusion and equality for persons with disabilities:” (submitted during the High Level Political Forum 2019), page 6, available at https://sustainabledevelopment.un.org/content/documents/23201Persons_with_Disabilities_Stakeholder_Group__Position_Paper__HLPF_2019.pdf

[8] Disability, gender, and employment relationships in Africa: The case of Ghana (nih.gov)

[9] Thematic study on the work and employment of persons with disabilities: (un.org), para. 52.

[10] UN Economic Commission for Africa; Africa’s youth and prospects for inclusive development regional situation analysis report https://www.ohchr.org/Documents/Issues/Youth/UNEconomicCommissionAfrica.pdf

[11] ILO Policy Brief June 2020, COVID-19 and the World of Work, Ensuring the inclusion of persons with disabilities at all stages of the response. wcms_746909.pdf (ilo.org)

This chapter has been developed from research conducted under the fellowship awarded to Dorothy under the "Making DPOs equal partners of inclusive development in Africa" project, funded by the Norwegian Agency for Development Cooperation (Norad), implemented by the International Disability Alliance and its members.[12] The focus of this particular fellowship was on women and youth with psychosocial disability and the right to employment under Article 27 of the CRPD.

Analytical Framework

The framework of this research initiative is based on the human rights related to work and employment in the CRPD and other human rights frameworks.

The right to work is a fundamental human right. The Universal Declaration of Human Rights recognizes that everyone has the right to work, to free choice of employment, to just and favorable conditions of work, and to protection against unemployment (art. 23, para. 1).[13] The right to work has been reiterated in different contexts in a number of human rights instruments, and as human rights are indivisible and interdependent, they must all be read as a continuum.

Referring specifically to persons with disabilities, Article 27 of the Convention sets out the right to work of persons with disabilities and constitutes one of the most detailed provisions of the Convention.

The Article opens with the reiteration of the right of persons with disabilities to work on an equal basis with others and emphasizes the free choice and acceptance of work, elimination of discrimination (including through provision of reasonable accommodation), and a work environment that is open, inclusive, and accessible to persons with disabilities. The Article also reflects the eight fundamental conventions related to rights at work as identified by the ILO[14] by addressing access to labor

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[12] The project, implemented by the International Disability Alliance and the African Disability Forum, is working towards influencing the disability rights movement to shape the development agenda in sub-Saharan Africa towards the full and effective realization of human rights of persons with disabilities has increased. One important component of the project is supporting IDA's members' members in sub-Saharan African to develop and strengthen underrepresented groups of persons with disabilities by the disability rights movement, to build evidence for advocacy and engage in using this to reform laws, policies, programs, and/or hold governments and INGOs accountable for progress in leaving no person with disability behind. To this end, fellowships were awarded to members of IDA members of Down Syndrome International, Inclusion International, World Blind Union, World Network of Users and Survivors of Psychiatry, and World Federation of Deafblind. Dorothy Nakato is a fellow with the World Network of Users and Survivors of Psychiatry. This project is specifically focused ensuring that policies, programs, and investments necessary to realize their human rights are developed, implemented, and monitored with clear and evidence-based guidance and their direct participation, through their representative organizations. https://www.internationaldisabilityalliance.org/norad

[13] See the Universal Declaration of Human Rights art. 23, para. 1.

[14] Forced Labour Convention, 1930 (No. 29), and the Protocol of 2014 thereto; the Freedom of Association and Protection of the Right to Organise Convention, 1948 (No. 87); the Right to Organise and Collective Bargaining Convention, 1949 (No. 98); the Equal Remuneration

and trade union rights, general technical and vocational guidance programs, employment services, career advancement, job retention, and return to work programs. Persons with disabilities are protected from servitude, slavery, forced or compulsory labor, on an equal basis with others. Importantly, the Article also addresses inclusion within the private sector. This Article has been further supported by the recent General Comment on Article 27 issued by the Committee on the Rights of Persons with Disabilities.[15]

Article 11 of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) mandates States Parties shall take all appropriate measures to eliminate all forms of discrimination against women in the field of employment, in order to ensure, on a basis of equality of men and women, the same rights.

Article 15 of the African Charter on Human and People's Rights[16] provides for every individual's right to work under equitable and satisfactory conditions and for equal pay for equal work.

Article 3(1) of the Protocol to the African Charter on the Rights of Women in Africa and the right to work reaffirms women's right to dignity inherent in all human beings.[17]

The researcher also considered the legal frameworks of the different countries included in the study (Uganda, Kenya, Malawi, Zambia, and Nigeria), such as national constitutions, employment legislations, disability legislations, mental health legislations, among others.

An important guiding point to this research were Dorothy's anecdotal experiences from her peer support work on the challenges that were being experienced by women and youth with psychosocial disabilities, which developed into a study.[18] In this chapter, based on the case studies collected during the research, the authors seek to highlight:

- Barriers that women and youth with psychosocial disabilities face in access to gainful employment in the open labor market
- Key elements that support access to the rights of women and youth with psychosocial disabilities to work and employment under Article 27 of the CRPD
- Recommendations to States Parties and Organizations of Persons with Disabilities towards realization of the rights under Article 27 for women and youth with psychosocial disabilities

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Convention, 1951 (No. 100); the Abolition of Forced Labour Convention, 1957 (No. 105); the Discrimination (Employment and Occupation) Convention, 1958 (No. 111); the Minimum Age Convention, 1973 (No. 138); and the Worst Forms of Child Labour Convention, 1999 (No. 182).

[15] Committee on the Rights of Persons with Disabilities, General Comment No. 6 (2018).

[16] https://au.int/sites/default/files/treaties/36390-treaty-0011_-_african_charter_on_human_and_peoples_rights_e.pdf

[17] The Protocol to the African Charter on the Rights of Women in Africa and the right to work, https://www.un.org/en/africa/osaa/pdf/au/protocol_rights_womeafrica_2003, Article 3(1).

[18] See "Researcher Standpoint and Background" as an annexure below.

Barriers and Enablers: Learnings from the KII Discussions

The study found that in general, employment is a huge challenge in these countries, especially for youth and women, due to many factors including lack of spaces and supports created for youth to join employment, social and cultural norms that hinder women from accessing employment, lack of policies and procedures for employment for the general public, and lack of disaggregated data on employment.

The employment situation for youth and women with psychosocial disabilities is worse due to the misconceptions and prejudice against persons with psychosocial disabilities.

Youth and women with psychosocial disabilities face enormous challenges. Being mostly employed in the informal sector, they have less employment opportunities due to their invisibility in the mainstream of society. There is also no disaggregated data by age, sex, or disability, which poses the challenge of finding out how many persons with psychosocial disabilities are in employment.

In this section, general learnings will be presented, along with select case studies from the research.

Job Placement and Affirmative Action

Most respondents were not aware of the specific policies addressing job placement for persons with disabilities in their countries. This lack of awareness means that employers, especially in the private sector, and persons with disabilities themselves cannot benefit from these policies. It is important that States popularizes these polices including through the media.

In addition, specific policies addressing job placement for persons with disabilities in all the five countries are not sufficient and do not promote employment of persons with disabilities. For example, in Uganda, the Income Tax Act provides for a 20% tax incentive to every private company where 5% of its employees are persons with disabilities. However, this tax incentive is not attractive enough for the private companies for it has not yielded any results.

It is important to ensure that affirmative actions are in line with the Convention. Some examples of affirmative action consistent with the Convention include:[19]

(a) Ensuring that employers do not restrict persons with disabilities to certain occupations, reserved jobs, or specific employment units.
(b) Ensuring that employers do not restrict persons with disabilities from opportunities for promotion and career growth.

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[19] General Comment No. 8, para. 42.

(c) Taking steps to ensure that work promoted under these measures does not constitute "fake" employment, whereby persons with disabilities are engaged by employers but do not perform work or do not have meaningful employment on an equal basis with others.
(d) Incorporating a disability, gender, and age perspective across the organization.

Recruitment Processes, Including Advertising, Selection, and Interviewing

Most of these processes do not include and address the needs of women and youth with psychosocial disabilities seeking employment. During interviews, most persons with psychosocial disabilities do not disclose their disabilities owing to the fact that if disclosed at that stage, there will be high chances of not continuing to the next stage due to prejudices and misconceptions that employers have about psychosocial disabilities such as "incompetency," "dangerous," and "destructive." Privacy is an important issue to be considered as consequences of disclosing a disability can expose a person to stigma and discrimination.[20]

Case Study: The Job Interview (Nigeria)

> "I must have passed the interview but due to my disclosure, I lost the employment opportunity"

A young woman with a psychosocial disability living in Nigeria shared that she was called for an interview in which she did well. At the end of the interview, she disclosed that she had a psychosocial disability. She observed a negative facial expression from the interviewers. They told her they would contact her for the next steps. She never heard back from them.

Participation of OPDs and Professional Training Programs for Staff

The research found that to some extent public and private employers have conducted training programs on disability awareness for staff, but there has been no specific training on enabling inclusion of person with disabilities at workplaces. In the case of Uganda, the National Union of Persons with Disabilities (NUDIPU) confirmed that training on inclusion of persons with disabilities at workplaces for staff is mandated in human resource manuals but are not implemented. NUDIPU is keen on conducting staff orientation trainings including trainings on disability inclusion at workplaces in

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[20] From the General Comment No. 8, para. 74: Respect for the privacy of employees with disabilities requires employers to obtain the consent of an employee with disabilities to share the disability – or impairment-related information that is disclosed to them, for example, with the staff in the human resources department.

the near future. Many organizations choose to put the burden of sensitization on the person with disability who has been hired. Not only is that problematic but also, as explained by the CEO of NUDIPU, "It does not guarantee that when you have a disability, you know disability inclusion." That underlines the importance of conducting trainings on inclusion of person with disabilities at workplaces with proper methodologies that are based on a cross-disability and equity lens.

Kenyan OPDs got an opportunity through Inclusion Works (IW) project to conduct trainings on inclusion of persons with disabilities at workplaces. In Uganda and through IW, human resource managers through the Human Resource Managers' Association of Uganda (HRMAU) benefitted from sessions on disability inclusion.

Case Study: Isaac (Uganda)

> "I am enjoying my work, feel supported and I do not experience any stigma at the workplace"

Isaac is a youth with psychosocial disabilities, aged 25, from the Jinja District of Uganda. He is a member of the TRIUMPH Mental Health Support and Recovery Program (TRIUMPH). He applied for a job through the Inclusion Works program[21], which links youth with disabilities to potential employers. He feels that he benefited greatly from this experience.

The Inclusion Works program worked in close consultation with TRIUMPH. This helped to support Isaac through peer support, sharing work-related issues with peers and mentors, and access to psychosocial support. TRIUMPH also supported the employing organization – Child Restoration Outreach (CRO), Jinja – to create an enabling work environment, including creating a resting space for any staff who may need it on occasion.

CRO staff received training on disability inclusion at the workplace from the National Union of Disabled Persons of Uganda (***NUDIPU***), an umbrella organization of persons with disabilities. CRO representatives reported appreciating working with persons with psychosocial disabilities as part of the team that together brings development of the organization. After his internship of 3 months, this organization retained him as a full staff member. CRO staff reaffirmed that working with Isaac helped them to also undo the fears, the stigma that they had working with persons with psychosocial disabilities.

Addressing Discrimination and Harassment

The research found that discrimination on the basis of disability is prohibited in most of the countries' legal framework including their constitutions, equal opportunity laws, and employment laws. In International Human Rights Law, discrimination

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[21] https://www.internationaldisabilityalliance.org/inclusion-works

takes several forms and may occur simultaneously as well: direct discrimination, indirect discrimination, denial of reasonable accommodation, harassment, and discrimination by association. This expansive definition is not always reflected.

Harassment is a form of discrimination when unwanted conduct related to disability or other prohibited grounds takes place with the purpose or effect of violating the dignity of a person and of creating an intimidating, hostile, degrading, humiliating, or offensive environment.[22] This is commonly experienced by persons with psychosocial disabilities at the workplace. Protection from harassment in connection with work and employment extends throughout the employment cycle and States Parties must implement effective remedies through the enactment and enforcement of specific and comprehensive antidiscrimination legislation.[23]

Case Study: Mark (Uganda)

> "My supervisor at one time doubted whether I am telling the truth about my disability since it is invisible"

Mark is a 28-year-old youth with psychosocial disabilities. He disclosed his disability to his employer along with the work schedule adjustments he needed, which were initially agreed upon. Even so, his own suggested adjustments were not respected, and measures were taken purportedly in his best interests, but hampered his full and effective participation at the workplace.

Along the course of employment, his supervisor violated the agreement especially on work schedules and he was called to work longer hours and more days than initially agreed.

At one point, he requested to take a week off while taking medication as he had gone for a medical review and was not feeling well. The medication he was prescribed required him to get adequate sleep. On informing his supervisor, the response was that the supervisor was "...tired of those issues of yours - going for medical reviews" and instead told him to go for a month's leave, which he never asked for. These insensitive and incapacitating words and gestures made him feel guilty and reinforced the belief that disability is an individual problem.

Providing Reasonable Accommodation

The research found that in all the countries there has been no complete harmonization of all the domestic laws with the CRPD. The mandate to provide reasonable accommodation has not been explicitly stated in the domestic laws, including the employment laws of the different countries as provided in Article 2 of the CRPD.

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[22] Committee on the Rights of Persons with Disabilities, General Comment No. 6 (2018), para. 18.

[23] Committee on the Rights of Persons with Disabilities, General Comment No. 6 (2018), para. 22.

In Uganda, reasonable accommodation is recognized under the Persons with Disabilities Act of 2020. However, it has not entirely come into force since the Government is still in the process of issuing regulations to support the legislation. In Kenya, the circular on remuneration for a personal guide for public officers living with disability[24] issued by the Salaries and Remuneration Commission has provisions for support but does not include persons with psychosocial disabilities. There are efforts to amend the Kenya Persons with Disabilities Act 2003, with a proposal on reasonable accommodation.[25]

Reasonable accommodation is a relatively new concept that governments are struggling to understand.[26] There is an added complexity when it comes to persons with psychosocial disabilities, compared to other disabilities that are generally accepted by employers as requiring accommodations that are tangible: for example, customized seating, assistive devices and technology, and sign language. In that sense, the supports required by persons with psychosocial disability are not obvious and there can be considerable diversity in the range of supports that persons with psychosocial disability need to thrive in the workforce.

There is no exhaustive list of reasonable accommodations possible, nor is it desirable. The CRPD recognizes the diversity of the disability movement. Even so, from the research, some examples of reasonable accommodations that were proposed by persons with psychosocial disabilities included:

- Time off for follow-up visits to clinic/psychiatrist/psychologist.
- Flexible time to accommodate effects of medication such as drowsiness.
- Frequent breaks.
- Extended sick leave should a relapse occur.
- Reduced stress working environment.
- Use of email for daily instructions.
- Minimize distractions by enclosed office.
- Need for job coach or mentor.
- Easing the employee into changes in the organization.
- Breaking large tasks into small achievable tasks that promotes motivation and improves the mood of the employee.
- Access to peer supports.
- Working from home if one chooses.

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[24] https://repository.kippra.or.ke/bitstream/handle/123456789/3825/Remuneration-for-a-Personal-GuideFor-Public-Officers-Living-With-Disability-Ref-No.SRC_TS_NCPWD_3_18_80-Dated-26th-August-2019-1.pdf?sequence=1&isAllowed=y

[25] See, for instance, a proposed amendment from 2020, the Persons with Disabilities Bill 2020, http://www.parliament.go.ke/sites/default/files/2021-03/The%20Persons%20with%20Disabilities%20%28Amendment%29%20Bill%202020.pdf where

[26] This is reflected in the General Comment No. 6 on equality and nondiscrimination CRPD/C/GC/6.

Case Study: Support from Staff (Uganda)

A woman was hired by an electricity transmission company and did not disclose the fact that she had been diagnosed with bipolar disorder at the time of interview. After a period of 2 years of great work and having shown greater potential over other employees, she experienced a mental health-linked relapse. It was like a surprise to the employer, but because the employer had appreciated her potential, the employer and fellow staff have supported her to continue working. She has been with the same company for close to 8 years now.

Equal Pay for Equal Work

In the formal employment sector, there is likely to be equal pay for equal work for women and youth with psychosocial disabilities. However, if the pay is based on output, which is becoming increasingly common in the "gig economy," women and youth with psychosocial disabilities will face barriers, because reasonable accommodation is still unknown and unavailable for them to effectively participate in the workforce, thus affecting their equal pay for equal work.

In the informal sector, women and youth with psychosocial disabilities face great challenges to get equal pay for equal work. The common misconception is that employers are doing them a favor and also that women and youth with psychosocial disabilities, especially those in rural areas, are not right holders. Women with psychosocial disabilities are often paid in kind instead of money.

Career Advancement

Inclusive employment does not stop at the point of entry into the workplace. Persons with disabilities should also have access to career advancement opportunities including the right, on an equal basis with others, to be considered for promotion through fair, merit-based, and transparent processes. However, persons with disabilities experience higher barriers to career advancement for a variety of reasons, and this is even more so for women with disabilities. The CRPD Committee has recommended that States Parties evaluate direct and indirect barriers to career advancement encountered by persons with disabilities, in particular by women with disabilities.[27]

Case Study: Stigma-Based Evaluations (Uganda)

A woman with psychosocial disabilities was appointed as a head teacher in one of the private schools in Uganda. After 1.5 years of excellent performance, she experienced a mental health episode. She was hospitalized, and after 2 months of recovery, she felt she was ready to return to work, though she still experienced

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[27] Committee on the Rights of Persons with Disabilities, General Comment No. 8 (2022), para. 36.

physical weakness and drowsiness as side effects of the medication. She faced high levels of exclusion and stigma from her fellow teachers to the extent that she felt isolated at school.

The school Board of Directors held several meetings to dismiss her based on fears of nonperformance and that she could endanger learners. With the support of an OPD – TRIUMPH – representing persons with psychosocial disabilities, the school Board of Directors was supported to retain her, but she was still demoted to a class room teacher. She did not know that she could request for reasonable accommodation and the school did not know how to support her.

Access to Technical and Vocational Training and Rehabilitation

The study found that there is little access to technical and vocational trainings for women and youth with psychosocial disabilities. This is because women and youth with psychosocial disabilities do not have access to information about the training opportunities, especially those in rural areas. Technical and vocational training is important, because women and youth with psychosocial disabilities face greater challenges in the formal education systems coupled with lack of adequate community support services. As a result, very few are able to complete school to be able to compete favorably in the open labor market.

There is also no reasonable accommodation in the training institutions for persons with psychosocial disabilities. The instructors in these institutions are not trained on disability inclusion on how to work with a diversity of disability groups. This leads to many dropping out before completion of the course.

Case Study: No Accommodation (Malawi)

At an institute for technical and vocational training, a young woman with psychosocial disability was keen on joining a course. She shared that she has social anxiety so she would perform well working with few people like groups of 10 or less or one to one. The institution said that they could not offer such a service. She therefore could not benefit from the training.

Access to Self-Employment, Entrepreneurship, the Development of Cooperatives, and Starting One’s Own Business

Due to a labor market that is often unfriendly to persons with disabilities, self-employment has often been seen as one of the few options available – indeed, it is for many persons with disabilities the only real option to work.

The study found many mainstream economic empowerment programs for women and youth that would benefit those with disabilities such as Youth Livelihood Programs, Women Empowerment Fund, and other disability specific programs being implemented in different countries. But it can be surmised that not many women and youth with psychosocial disabilities benefit from these programs.

In the countries examined, there was no process for ensuring the inclusion of the diversity of persons with disabilities. The procedure for assessment of psychosocial disability was also problematic. Issues around processes mean that people who do not have disabilities that are evident, including psychosocial disabilities, are more at risk of being excluded. Individuals and groups are required to register and open bank accounts before their application, which are made in English, can even be considered. This creates additional barriers for persons with disabilities. There is also a lack of disaggregated data by sex, age, and disability on the beneficiaries of these programs.

Exploitation and Forced Labor

It is evident that women and youth with psychosocial disabilities are faced with situations of forced labor and exploitation. As has been elaborated in the General Comment, States Parties should pay attention to the right of persons with disabilities to choice, consent, and freedom from coercion. The risk of coercion stems from the fact that persons with disabilities often face wider social vulnerability, a lack of meaningful alternatives, and relations of dependency or care that become exploitative. This risk needs to be considered for the purposes of understanding whether consent has been given.[28]

Women and youth with psychosocial disabilities are forced to do work that they have not freely chosen. And this mainly stems from their families, who see them as a "burden" and unable to contribute anything to their well-being and that of their family, increasing family expenses in terms of psychiatric medicines, food, and loss of time and work for the caregivers. So, they are at times forced by family members to engage in work they have not chosen but instead chosen for them by family members or forced to engage in domestic work that is unpaid.

Case Study: "Keeping Her Occupied" (Uganda)

A young woman with psychosocial disabilities who has been employed in an office was told to chase away loitering goats which were eating up flowers. This young lady spent a whole day under the sun, sweating, using a lot of energy throwing sticks at the stubborn goats. Her line manager explained that this was the only way to keep her occupied. The researcher also found out that there was no pay for the work done, which clearly makes this an instance of exploitation.

Impact of COVID-19

Inequalities for persons with psychosocial disabilities with regards to work and employment existed before COVID-19. The pandemic, however, has vastly

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[28] Committee on the Rights of Persons with Disabilities, General Comment No. 8 (2022), para. 52.

exacerbated the situation. Increased stress and anxiety have been difficult for persons with psychosocial disabilities, leading to frequent relapses and many people experiencing mental breakdowns.[29]

The breakdown in the support systems for persons with psychosocial disabilities like peer support group meetings stopped due to the lockdown measures, inaccessible psychiatric and psychosocial support services, inability to take walks which is therapeutic to some persons with psychosocial disabilities, etc.

There has also been a documented increase in abuses and human rights violations towards women and youth with psychosocial disabilities.[30] While many pivoted easily into the online world, the same was not as easy for women and youth with psychosocial disabilities.

Observations on Legal Reform and Policy Initiatives

Following the review, in these countries, there has been a progress on legal reforms and policy initiatives.

In Uganda

IGA Daniel v. AG[31] is a strong step forward for the equality rights of persons with disabilities. In particular, the Constitutional Court of Uganda at Kampala reviewed the human rights framework applicable in Africa, the Ugandan Constitution, and previous Court decisions and then decided as follows at page 22, lines 11–17:

> "Following the reasoning and decision in the above case, we find that the language of section 130 of the Penal Code Act is dehumanizing. The words "idiots" and "imbeciles" are derogatory and detract from the dignity that should be accorded to all disabled persons under Article 24. We find this is not permissible and justifiable as the language contravenes Articles 20, 21(1), (2) and (3), 23, 24, 28 and 35 of the Constitution"

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[29] See also Ebuenyi et al. (2022).

> "In the face of the existing challenges faced by people with psychosocial disabilities and the inaccessibility of social assistance provision, the pandemic containment measures worsened participants' psychological well-being. The lockdowns and other restrictions caused much worry and distress for persons with psychosocial disabilities. Participants reported that they felt hopeless, helpless and depressed in the worst times of the crisis."

[30] See, for example, UNFPA and Women Enabled, "The impact of COVID-10 on women and girls with disabilities" https://www.unfpa.org/sites/default/files/pub-pdf/NEW_UNPRPD_UNFPA_WEI_-_The_Impact_of_COVID-19_on_Women_and_Girls_with_Disabilities.pdf

[31] Center for Health, Human Rights and Development (CEHURD) and Iga Daniel vs. the Attorney General https://www.cehurd.org/wp-content/uploads/2015/11/constitutional-petition-64.pdf

The Uganda Persons with Disability Act, 2020, explicitly has a provision on nondiscrimination in employment for persons with disabilities.[32] It further recognizes a failure to provide reasonable accommodation as discrimination.

In Kenya

The Access to Government Procurement Opportunities (AGPO) initiative[33] for women, youth, and persons with disabilities was operationalized in the Public Procurement and Disposal Act 2005. In the Public Procurement and Disposal (Preference and Reservations) Amendment Regulations, 2013, procuring entities are mandated to allocate at least 30% of its procurement spending for the purposes of procuring goods, works, and services from micro and small enterprises owned by youth, women, and persons with disabilities.[34] However, it has been found that the scheme has not benefitted persons with disabilities as much as it was intended, with currently only 4.9% of businesses being owned by persons with disabilities.[35] The situation regarding underrepresented groups of persons with disabilities is even more concerning, for instance, of the 3000 odd persons with intellectual disabilities that are members of the Kenyan Association of the Intellectually Handicapped, none of them has accessed this scheme, attributing this to the qualifications for the process, which are quite onerous for small organizations run by persons with disabilities.[36] It is important for the authorities to capture disaggregated data on the persons with disabilities who do access this program and to ensure that in the overall 30%, each beneficiary group is allocated a 10% quota, for it to be truly effective.

Recommendations

This section of the study offers general recommendations to States Parties and also specific recommendations to organizations of persons with psychosocial disabilities.

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[32] Uganda Persons with Disability Act, 2020, https://ulii.org/akn/ug/act/2020/3/eng%402020-02-14

[33] http://wtochairs.org/sites/default/files/KENYA%20ASSESSMENT%20OF%20ACCESS%20TO%20GOVERNMENT%20PUBLIC%20PROCUREMENT%20OPPORTUNITIES%20FOR%20

[34] Regulation (31) (1). This particular kind of clause has been highlighted by the CRPD Committee with caution: while procurement measures giving preference to enterprises run by or employing persons with disabilities is a form of affirmative action, preferential purchasing policies that promote or support segregated employment are not affirmative action measures consistent with the Convention (Committee on the Rights of Persons with Disabilities, General Comment No. 8 (2022), paras. 41 and 42).

[35] Hivos, *Kenya's Efforts to Empower Women, Youth and Persons with Disability through Public Procurement* https://hivos.org/assets/2021/02/Agpo-Report-Web-version-Full-Report.pdf

[36] Interview with Fatma Haji, KAIH, February 2023.

Recommendations to States Parties

States are obligated to respect, protect, and fulfill the right to inclusive employment in its full presentation under Article 27. This entails:

- Removal of all laws and policies or guidelines that prohibit or interfere with the employment of persons with psychosocial disabilities, including laws related that interfere with the equal recognition before the law of persons with psychosocial disabilities.
- Prohibiting disability-based discrimination, including workplace harassment, in the area of work and employment, and ensuring that legislation creates the obligation to provide reasonable accommodation and stipulates that denial of reasonable accommodation constitutes discrimination.
- Ensuring that private sector and informal sector employers do not discriminate against persons with psychosocial disabilities.
- Promoting widespread understanding and acceptance among employers, including in the private sector, as well as persons with disabilities themselves, of the concept of reasonable accommodation and the consequences of unlawful denial of the same.

In addition, States Parties should adopt positive measures, including affirmative action to increase employment of persons with psychosocial disabilities in the public and private sectors, including affirmative action measures which are non-discriminatory and fully inclusive of persons with disabilities.

Access to employment does not stand alone; there are multiple rights that, when realized, support the realization of Article 27. This includes inclusive education, the right to live independently and within the community, the implementation of social protection schemes that support addressing disability-related costs in seeking employment, and access to assistive devices, among others. This is especially important for persons with psychosocial disabilities who are moving from institutional care into the community as Article 19 of the CRPD is progressively realized. States must also mobilize resources for persons with psychosocial disabilities to start their own enterprises by providing access to financial services, seed funding, etc., for persons with psychosocial disabilities to start their own enterprises.

Both State actors and employers carry the responsibility of ensuring that all positive measures or programs are designed and promoted in a way that recognizes the value of diversity in the workplace and equal career development for all.

States Parties should ensure equal access to vocational training and rehabilitation programs that are nondiscriminatory, accessible to, and inclusive of all persons with disabilities, especially those experiencing multiple and intersecting forms of marginalization, including through providing reasonable accommodation.

States Parties must include indicators on disability when collecting data on employment so as to allow for well-informed and targeted efforts to be made to improve the employment situation of persons with disabilities, and capture data on the inclusion of underrepresented groups.

States must involve representative organizations of persons with disabilities in the design, implementation, evaluation, and monitoring of all policies and programs related to the employment of persons with disabilities. An independent mechanism to monitor the implementation of the Convention, as provided for under Article 33 of the Convention, can play a role in helping to create stronger links between social partners already engaged in employment policy and monitoring and representative organizations of persons with disabilities.

Recommendations to the Private Sector

While the private sector engagement depends a lot on the involvement of the State (by framing laws, regulations, and offering incentives) and the OPDs (for providing expertise), still there are a few suggestions for the private sector as they are increasingly being seen as desirable employers of persons with disabilities with several private sector-led initiatives to promote employment of persons with disabilities.[37]

- National Chambers of Commerce and Industry should engage with OPDs to learn about good practices for the employment of persons with disabilities, including psychosocial disabilities.
- Human Resource Managers' Associations and similar bodies should develop, in consultation with OPDs, equal opportunity policies for all employees, including for persons with disabilities. This should include clear policies on reasonable accommodation and supports for the career path of persons with disabilities for industry-wide adoption.
- Recognition of private sector organizations that employ and successfully retain a diverse pool of persons with disabilities, including youth and women.

Recommendations to Organizations of Persons with Psychosocial Disabilities

OPDs have an important role in ensuring that persons with disabilities are aware of their rights and have the support of an organization to realize them. In the case of psychosocial disability, this is especially important, as conditions remain extremely medicalized and a shift to the social model is happening gradually. OPDs must:

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[37] For example, the Valuable 500, which is a global collective of 500 CEOs and their companies committed to employing persons with disabilities and innovating for disability inclusion. https://www.thevaluable500.com/

- Build the capacities of women and youth with psychosocial disabilities on the CRPD to know and advocate for their rights, and to also include more women and young people in leadership roles.
- Raise awareness on the rights and potential of persons with psychosocial disabilities. This will combat stigma and misconceptions about persons with psychosocial disabilities and also combat gender stereotypes against women and youth with psychosocial disabilities.
- Build partnerships and collaborations with both public and private employers to give support and job coaching to employees with psychosocial disabilities.
- Conduct trainings on inclusion of persons with disabilities at workplaces in different workplaces (private and public) including OPDs.
- Increase advocacy for inclusion of persons with psychosocial disabilities in all development spheres.
- Advocate for inclusive policies at workplaces such as gender policies alongside Human resource policies.

Good Practice

TRIUMPH is an OPD in Uganda that advocates for the inclusion and rights of persons with psychosocial disabilities and also employs persons with psychosocial disabilities. They have identified some good practices in their experience that have worked for inclusive employers.

Mentorship and job coaching.

Appreciating the diversity and value that each one of them brings to the organization.

Avoid work-related stress that can result in many errors.

Sharing love, and everybody comes to work with the courage that she/he is loved and valued. This is because persons with psychosocial disabilities come from a journey full of loss and suffered violence.

Respecting the recovery journey using the World Health Organization (WHO) Recovery wellness plan. Here we ask “What keeps you well at work? And what causes you to become unwell?”. Share with the management the support that you need to be productive at work.

Using empowering words; consistently communicating their value to the organization.

Entering from the point of strength, not only bring out the negatives about the employee.

Listen nonjudgmentally.

Determine not to give up on an employee with psychosocial disabilities.

Promoting exposure since most persons with psychosocial disabilities are not even exposed due to many barriers they face in the society.

Conclusion

Notwithstanding the specific manner in which the right to dignified employment has been articulated under the human rights instruments and in CRPD Committee jurisprudence, the trickle-down effect into national legislation and frameworks, and further into the reality of labor force participation, is yet to be seen. The labor force participation rate of women and youth with psychosocial disabilities in Africa continues to be very low and undesirable when compared to the general population and when compared to the different categories of disabilities.

The dearth of context-relevant scientific evidence on issues of persons with psychosocial disabilities, particularly on the situation of women and youth with psychosocial disabilities in Africa, is of concern. There is a lack of evidence on work and employment of women and youth with psychosocial disabilities in Africa. It is hoped that this study will benefit the policy makers, governments, public and private employers, and OPDs. The experience of women and youth with psychosocial disability in the labor force is also essential for any study or programs on the transition from informal economy to formal economy for rural women and youth with psychosocial disabilities, as well as while studying access to social protection.

In this study, it is evident that women and youth with psychosocial disabilities are willing and can work on an equal basis with others, given the appropriate support they require to perform the inherent requirements of their work on an equal basis with others. It highlights the numerous challenges they face in their course of work and employment, including: disclosure of mental health impairments amounting to discrimination; failure to articulate and understand reasonable accommodation; lack of meaningful alternatives and situations of coercion; unequal pay and recognition for work of equal value; and the myriad ways in which women and youth with psychosocial disabilities experience multiple and intersectional discrimination in work.

However, this study also highlights the facilitators to gainful employment for women with psychosocial disabilities, such as empathetic employers and simple measures for reasonable accommodations. Other factors that have shown to be important are closer and meaningful consultation and involvement of OPDs of persons with psychosocial disabilities right from the hiring process; linking women and youth with psychosocial disabilities to potential employers; and mentorship and coaching.

The first-person accounts that were shared with the primary researcher also underline the transformative nature of steady and dignified employment. There is a global shift in medicalized approaches to mental health to a recognition that socioeconomic factors, including unemployment, have a huge impact on mental health (Macintyre et al., 2018). While this was not something focused on during the KIIs, where participants received support, they appeared to have overall better outcomes in other facets of their lives. Any measures to improve outcomes for persons with psychosocial disabilities and to support their inclusion in the community must also include measures towards inclusive employment. As we move towards implementation of the deinstitutionalization guidelines[38] and discussions on community inclusion[39], it becomes essential to also consider the barriers being experienced by women and youth with psychosocial disabilities and to address them by scaling up some of the good practices that have been seen.

Annexure 1: Key Terminologies

United Nations Convention on the Rights of Persons with Disabilities (CRPD): An international human rights treaty of the United Nations intended to protect the rights and dignity of persons with disabilities.

Disability: The preamble of the CRPD recognizes that “disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.”

Persons with disabilities: CRPD Article 1 states that “persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

Organizations of persons with disabilities (OPDs): These are organizations established predominantly with the aim of collectively acting, expressing, promoting, pursuing, and/or defending the rights of persons with disabilities. OPDs. They employ, are represented by, entrust or specifically nominate/appoint persons with disabilities themselves. They may represent one or more constituencies of persons with disabilities or operate cross disability. General Comment No. 7[40] gives more clarity on what OPDs are, as opposed to organizations working for persons with disabilities.

Psychosocial disabilities: The Mental Health and Human Rights Resolution of the Office of the United Nations High Commissioner for Human Rights (OHCHR, 2017) defines persons with psychosocial disabilities as, “persons who, regardless of self-identification or diagnosis of a mental health condition, *face restrictions in the exercise of their rights* and *barriers* to *participation* on the basis of an *actual* or *perceived* impairment.”

The term “**work**” is broad and includes unpaid work in the home or in a family enterprise, paid work for another person or organization in the formal or informal economy, and self-employment.

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[38] Committee on the Rights of Persons with Disabilities, Guidelines on deinstitutionalization, including in emergencies (2022) https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpdc5-guidelines-deinstitutionalization-including

[39] Office of the High Commissioner on Human Rights, Support systems to ensure community inclusion of persons with disabilities, including as a means of building forward better after the coronavirus disease (COVID-19) pandemic (2023) https://www.ohchr.org/en/documents/thematic-reports/ahrc5252-support-systems-ensure-community-inclusion-persons-disabilities

[40] Committee on the Rights of Persons with Disabilities, General Comment No. 7 (2018), paras. 10–14.

Livelihood is “the means by which an individual secures the necessities of life.” It may involve work at home or in the community, work alone or in a group, or for an organization, a government body, or a business. It may be work that is remunerated in kind, in cash, or by a daily wage or a salary.

Reasonable accommodation means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms. Discrimination on the basis of disability includes all forms of discrimination, including denial of reasonable accommodation (CRPD).

The **formal economy** is regulated by the government and includes employment in the public and private sectors, where workers are hired on contracts with a salary and benefits, such as pension schemes and health insurance.

The **informal economy** is the unregulated part of a country’s economy. It includes small-scale agriculture, petty trading, home-based enterprises, small businesses employing a few workers, and other similar activities.

Annexure 2: Researcher Standpoint and Background

Dorothy Nakato is an Indigenous woman with psychosocial disabilities from rural Uganda.

She experienced many barriers as a learner with psychosocial disabilities and earned a bachelor’s degree in commerce majoring in accounting from Makerere University. She began advocacy for persons with psychosocial disabilities in 2017. Dorothy is a co-founder and Executive Director of Uganda National Self-Advocacy Initiative (UNSAI) – A peer-led organization of persons with psychosocial disabilities.

After completing the Bridge CRPD-SDGs Training, Dorothy began passionately advocating for policy change through conducting research, writing policy papers, and storytelling on good practices. She has also been trained as an inclusive facilitator on the rights of persons with disabilities. She has been awarded fellowships with IDA-WNUSP, Transforming Communities for Inclusion, and the Zero Project as an Impact Transfer Fellow. Recently, Dorothy won a prestigious award with Zero Project on independent living and being included in the community for persons with psychosocial disabilities.

The International Disability Alliance (IDA) is a global alliance of organizations of persons with disabilities. With member organizations around the world, IDA represents the estimated one billion people worldwide living with a disability. This is the world’s largest – and most frequently overlooked – minority group. IDA aims to promote the effective and full implementation of the UN CRPD worldwide, as well as compliance with the UN CRPD within the UN system, through the active and coordinated involvement of representative organizations of persons with disabilities at the national, regional, and international levels. IDA supports organizations of persons with disabilities (OPDs) at national and regional levels through trainings and disseminating resources and information.[41]

Annexure 3: Methodology of the Study

As this project was being conceived in a context where there was little or no research, the methodology developed was around Key Informant Interviews (KII). The interviewees included youth and women with psychosocial disabilities both from the rural and urban areas.

Interviewees also included a few individuals in pivotal positions related to the implementation and/or monitoring of Article 27 of the CRPD, including organizations of persons with disabilities (OPDs), Human Rights Commissions, and government bodies. These interviews were conducted online because of COVID-19 restrictions.

A semi-structured interview guide was developed and used with 21 participants of the KIIs. A desk review was conducted to complement the qualitative interviews and contextualize individual experiences, as well as inform recommendations. Information was also collected from stakeholders by way of a discussion webinar on gainful employment for women and youth with psychosocial disability.

Limitations

There were several limitations to this study:

COVID-19 hindered face-to-face KIIs. Consequently, these were held online. This meant that many KII participants especially women and youth with psychosocial disabilities in the rural areas could not participate, as they do not have access to computers or smart phones.

Challenges posed by frequent internet disconnections with the KII participants consumed a lot of time.

With regards to Kenya, there was a specific challenge, as the researcher had not obtained a “research license.”[42] Government officials in Kenya who were contacted

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[41] For IDA, Amba Salelkar, Capacity Building Senior Technical Advisor, worked on this paper with Dorothy.

[42] In Kenya, a research license denotes permission to undertake research and is issued by the National Commission for Science, Technology and Innovation (NACOSTI) as per the ST&I Act to regulate and assure quality in science, technology, and innovation sector and advice government on matters related thereto. The Science, Technology and Innovation (ST&I) Regulations 2014, Legal Notice No. 108 (Research Licensing) Regulations, 2014, obligates all persons intending to undertake scientific research in Kenya to obtain a license in accordance with the Act. The Act states that any person undertaking or intending to undertake research in the country, or who accesses, handles, or transfers any materials or technology or moves it within, from, or into the country, shall apply to the Commission for the grant of a license. This was a learning for the overall fellowship program as well, in that in many country contexts, a license was required for research of any kind.

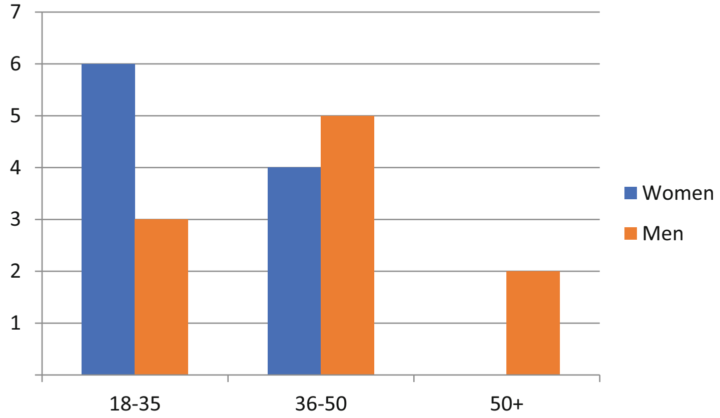

Fig. 1 Chart showing number of participants disaggregated by age and gender

for the research expressed an inability to participate as there was no research license issued by the National Commission for Science, Technology and Innovation to the researcher.

Participants

A total of 21(14 women and 7 men)[43] between the ages of 18 and 60 years responded to the Key Informant Interview. Most key informants were between the ages of 18 and 35 and women because they were directly targeted as they face multiple and intersecting forms of discrimination in the area of work and employment (Fig. 1).

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[43] Among the key informants, there was no one who identified as transgender or nonbinary people.

Holness, W. (2016). The invisible employee: Reasonable accommodation of psychosocial disability in the South African workplace. *South African Journal on Human Rights., 32*, 510–537. https://doi.org/10.1080/02587203.2016.1258197

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The “Welfareization” of Disability Incomes in Ontario

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Contents

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Abstract

Canada's disability income expenditures are rising at an unsustainable rate and the largest and fastest growing program is income or social assistance. We provide critical insight into the intricate drivers behind the alarming rise of disability income expenditures. Drawing on new data and original research, we review the many disability income support programs available to Ontarians, including recent changes to their eligibility and entitlement. We make a strong case for the profound effect that changes in the labor market are having on the ability of individuals to qualify for and to access programs. These trends continue into the third decade of the new millennium.

The report suggests that for many people with disabilities, social assistance is the only program able to provide the level of financial support and employment incentives they need to stabilize their circumstances and find a way to enter or reenter the workforce.

We examine regional similarities and differences, illustrate the complexity of our disability support systems, and call for reform through careful consideration of the whole system and all levels of government along with private and public sector employers and insurers.

Introduction

In 2013, I wrote a paper called the "Welfareization of Disability Incomes in Ontario."[1] Earlier that year, I wrote a similar paper with colleagues called "What is happening to disability incomes in Canada?"[2] Now a new Canada Disability Benefit (CDB) is on the policy horizon and was first announced on August 20, 2020, but yet to be implemented. Framework legislation was reintroduced as Bill C-22 in June 2022. This new benefit will be designed to stop welfareization and reduce poverty among people with disabilities. The real question is: will it?

Before the announcement, most of the disability benefits systems in Canada were tightening their belts, but the result was unprecedented growth in income assistance or social assistance programs for people with disabilities. In effect, social assistance programs played the part of the "volunteer" in the anecdote. Social assistance was the program that volunteered by default when the other programs and systems started to curtail their expenditures.

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[1] https://metcalffoundation.com/publication/the-welfareization-of-disability-incomes-in-ontario/

[2] http://www.ccdonline.ca/en/socialpolicy/poverty-citizenship/income-security-reform/disability-income-systems

In this context, it is not difficult to understand why caseloads comprised of low-income people with disabilities ballooned across Canada in the new millennium. Although many thought that social assistance based on disability must have become easier to obtain, the truth is that income and needs tested programs form the safety net that backstops all the other programs. And most other programs[3] simply grew more slowly when they went through cost containment exercises to curtail expenditure growth.

Some of the cost containment exercises in other disability incomes included:

- Workers' compensation programs that generally reduced benefits to a two-year maximum while reducing the reasons for which claims could be made.
- Tightened appeals mechanisms for programs run through Service Canada (CPP-D and EI) resulting in delays and fewer successful appeals.
- Changes to Veterans' disability benefits that restricted lifetime benefits to dwindling numbers of (legacy) Veterans of WWII and the Korean War.
- Cuts to private sector disability benefits that (again) generally restricted benefits to two years in duration.

The categorical result is an ever-growing share of expenditures in the disability income "space" that are paid through social assistance programs. The *welfareization* process continues to be unrelenting.

In fiscal 2018–19, the total expenditures of disability income programs in Canada, both private and public, were $37.8 billion. Of this amount:

- $11.4 billion were expended through social assistance program or 30.1% of the total. Social assistance is, by far, the single largest set of programs.
- Private programs accounted for $7.6 billion (20.1%).
- CPP-D and EI sickness combined spent $6.8 billion (18.0%).
- Workers Compensation programs spent $5.9 billion (15.6%).
- All disability tax measures combined spent $3.6 billion (9.5%).

In 2005–06, social assistance disability expenditures comprised 25.9% of disability income expenditures. This means – in comparison to later numbers – that the share of disability income accounted for by social assistance has risen by 8.6% since 2005–06. The shares comprised by other programs as a whole therefore continue to fall.

In human terms, people with disabilities now comprise a plurality of social assistance recipients in some provinces. In Ontario, the number of disability payments surpassed basic welfare payments in 2013. This was the first time since 1941 that this has happened. The human face of a welfare payment in Canada is now a person with disabilities.

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[3] EI sickness is the one notable exception.

Two Observations Concerning the Welfareization of Disability Incomes

Observation 1: Social assistance for people with disabilities will remain under pressure and subnational governments will continue to take opportunities to reduce expenditures. The implementation of a Canada Disability Benefit (CDB) could form one of those opportunities.

Observation 2: The relentless *welfareization* of disability benefits will only continue and the same fiscal pressures that force programs to reduce their eligibility and expenditures will mean that the implementation of a CDB could accelerate this process.

Social Assistance for Persons with Disabilities Will Remain Under Pressure and a CDB Must Recognize This Fact

Social assistance for people with disabilities has expenditure increase of over **91%** from 2005–06 to 2017–18 and increased its share of all disability income programs expenditures by **8.6%** to **30.1%**.

Accordingly, these programs have come under sustained fiscal pressure across Canada.

Alberta Premier Jason Kenney openly discussed cutting benefits in the Assured Income for the Severely Handicapped (AISH) in 2019 and 2020.

Ontario Social Services Minister Lisa Macleod announced that she would be tightening the disability definition in the Ontario Disability Support Plan (ODSP in 2018).

Similar threats to cut disability incomes have been made in Saskatchewan and Manitoba.[4]

Caseloads have risen for many different reasons. These include:

- Workforce changes whereby persons with disabilities and others do not have tenured salary and wage jobs that would trigger disability benefits.
- Cuts in some seven disability income systems leaving social assistance with more to do.
- Embedded rules that do not support work in older disability income systems (like CPP-D).
- Changes in medical treatment and especially advances in medicine and trauma treatment.
- Aging of the population.
- Inclusion of mood disorders and neuroses as disabilities.

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[4] https://north99.org/2019/12/13/conservatives-across-the-country-are-slashing-funding-for-disabled-canadians/

- The existence of separate social assistance disability programs and large differences in benefit levels between them and general social assistance.
- Reductions in OAS and GIS for immigrant seniors.
- Structural unemployment and underemployment among persons with disabilities and continuing economic stagnation.
- Lack of knowledge about disability income systems other than social assistance.
- Post-recession differences in employment patterns and benefits.
- Differing financial incentives among programs to bring people with disabilities back to work.
- Barriers to work in general.

Differences in caseload pressures are accounted for by the following factors that place greater pressure on provinces in Ontario and the West:

- Huge differences in EI coverage that reduces number of persons going on social assistance in eastern provinces. As regular social assistance is often a precursor to application for disability benefits, more robust regular EI appears to reduce social assistance overall.
- Social assistance disability programs that are smaller, less generous, and not separate in eastern provinces.
- Smaller social assistance based Disability components for First Nations in Eastern Provinces.
- A greater presence of interventions by other disability systems in eastern provinces.
- Fewer persons with disabilities that are ineligible for (or eligible for reduced benefits for) Old Age Security at age 65 in eastern provinces.

All of these factors figured in the decision of a majority of the provinces to claw back the CERB and all but one jurisdiction in respect of the CRB (BC).

In other words, provinces and territories that usually exempt federal tax benefits and especially those designed to meet other objectives succumbed to fiscal pressure to offset pandemic benefits.

This is a cautionary tale as a precedent has been set and provinces and territories may choose to vacate their place of providing basic disability benefits when the new CDB is implemented.

It will be important for the federal government to work together closely with provinces and territories to ensure that the CDB and social assistance programs both "stay in the game."

The federal news release of June 22, 2021, is somewhat ambiguous on this point as it says:

> The legislation also recognizes the leading role that provinces and territories play in providing supports and services to Canadians with disabilities and the importance of engaging with them in developing income and other supports.

But in an earlier passage, it says:

> The Canada Disability Benefit would supplement, not replace, existing federal and provincial-territorial supports with a goal of lifting hundreds of thousands of persons with disabilities out of poverty.

The clear problem for the federal government in supplementing provincial and Territorial benefits is that it would have **to “accept” 13 differing definitions of disability in the provinces and territories if it is to act as a top up to those benefits**.

This would be on top of “accepting” the disability definitions for the DTC, CPP-D, and Veterans’ benefits.

In this sense, the federal government would in fact be accepting a lead role while provinces and territories **could easily decide to lower their own benefits while allowing the CDB to fill the gap**.

If that were to be the case, an epic dogfight would ensue that helps neither side.

Clearly, there is much more to do.

But the federal government does need to recognize the massive financial pressures provinces and territories have borne in terms of the other disability income systems that have forced the expansion of the only set of disability programs that actually specifically assist people with disabilities living in poverty and in need.

What If the Welfareization of Disability Incomes Continues?

It will be important for the federal government to understand that pressures on all disability income programs except social assistance have been handled by offloading program expenditures onto social assistance across Canada.

Federal programs such as Veterans’ disability incomes have done it by tightening eligibility and placing time limits on the receipt of benefits. CPP-D EI and Veterans’ programs have done it by tightening appeals processes. Only relatively small federal programs like the DTC and EI sickness have not participated in decades-long cost controls.

At the provincial and territorial levels, most Workers’ compensation programs have cut back while private and public sector employer programs have placed stricter time limits on the receipt of benefits (usually in the two-year range).

In this sense, these programs have gotten used to *welfareizing* disability benefits.

In addition, accident insurance programs will have great pressures placed upon them to reduce premiums when a CDB is implemented unless mitigating action is taken beforehand.

The bottom line is that programs – that have gotten used to belt tightening with no real problem with offloading their clientele onto social assistance programs – will be no less interested in reducing expenditures with the advent of the CDP.

The real question is how to stop them and to stop the *welfareizing* that in many ways has provided the impetus to create a CDB in the first instance.

Two Case Studies

Angelica

Angelica, an office cleaner in her early 60 s who lives in Toronto, suffered her first major workplace injury after working for the government for 18 years. It was 1993. She was earning $21 an hour and regularly saving 5% of her net pay.

When she was injured, she immediately received workplace medical attention and was admitted to the hospital. She was given time off work at full pay and was able to deploy a robust bank of sick days. She received the benefits of a multifaceted workplace program that provided rehabilitation and other services including orthotic supplies, physiotherapy, and chiropractic treatment.

Following her in-house government coverage, Angelica qualified for workers' compensation. She also received 15 weeks of sickness benefits through employment insurance (EI) followed by regular EI benefits for the entire time she was off work.

Eighteen years later, in 2011, Angelica sustained a similar workplace accident. She now had 36 years' experience completing the same tasks in the same workplace.

However, 13 years earlier, in 1998, the work she was doing was contracted to an outside firm. The firm that successfully bid on the cleaning contract for the government offered Angelica a position as a self-employed contractor. In her new position she was offered a pay rate equivalent to the minimum wage. This meant that in 2011 Angelica was making $10.25 an hour – about one half (in nominal terms) of what she made before the 1998 changes.

At the time of Angelica's 2011 injury there was no workplace infirmary, so she phoned 911. New and heavy security in the government building delayed her hospital visit, increasing her stress.

As a self-employed contract worker she had no sick days and no other source of income. She had no access to rehabilitation and no workplace benefit program because, in technical terms, she was not an employee. She had to pay for her own orthotics, and because physiotherapy and chiropractic were delisted as insured provincial health care services, Angelica faced paying for any use of these services at full fee rates.

Angelica might have qualified for workers' compensation but she would have had to demonstrate to the Workplace Safety and Insurance Board that her relationship to the cleaning firm was, in principle, one of an employee.

Due to her injury, she is currently unable to return to work as a cleaner and is currently unemployed. She has the added worry that if her injury results in a permanent disability, she will not qualify for CPP disability benefits. She could have qualified if she had been making ongoing payments representing both the employer and employee portions, but she had determined that she was unable to afford these payroll levies on $10.25 an hour.

As a self-employed contractor, Angelica did not pay into EI and therefore does not qualify for the standard 15 weeks of EI sickness benefits or regular EI benefits.

Angelica has applied for welfare (Ontario Works) of $626 a month with an application in place for ODSP. The application is currently pending. If she takes early CPP, based on her earlier contributions as an employee, it will be deducted from her Ontario Works cheque (or ODSP if her application is accepted) at 100%. If she receives ODSP, she will be forced to apply for CPP-D. Otherwise, she can wait until age 65, although the higher CPP payment will further reduce her Guaranteed Income Supplement (GIS) entitlement.

Bob

In the 1990s, Bob was in his twenties and attending university. He had finally moved away from the small, isolated town in which he grew up. He was happy to be away from his dysfunctional family home and away from the beatings and the constant walking on eggshells.

Then, rather suddenly, he found he could not concentrate on his studies. Some very negative feelings started to come over him.

After talking to his friends, Bob came to the conclusion that he needed help and contacted the counseling services at the university. The counselors were sympathetic. They told him that a lot of young people have trouble with their studies. They offered study tips and assured him that what he was experiencing was a normal part of university life and he would get over it.

Bob did feel better for a while. He completed his year and secured a summer job. It involved strenuous physical activity. He liked it because it kept his mind away from that part of his psyche that was debilitating. But the next year, the dark feelings came back with a vengeance. This time, he went back to the counseling center. He received a similar response as the previous year, although one of the counselors worried about him and asked whether he would like to take some psychological tests. He agreed.

After a few weeks, the diagnosis came back that he was depressed and that he may be harboring deep hostilities toward some family members. Would he like to come back for some more testing? Once again, he agreed. Then, suddenly, he seemed to be doing a bit better, and the small dose of Valium they gave him seemed to be helping. Or was he imagining it?

Bob was going to graduate with a four-year degree, but he changed it to a three-year B.A. He went back to his summer job but was let go and then bounced around from job to job. He collected EI and, at the end of that, managed to hang on to work at a fast-food place but found it increasingly stressful.

Some days, he would feel so “up” he was sure he could take on the world. Others – now more frequent – were filled with darkness. He suffered greater anxiety at the thought of seeing either one of his parents. Eventually, Bob moved to a smaller town where rents were cheaper. He bunked in with two other fellows he knew from back in high school and applied for welfare. Months, and then years, went by in a fog.

Bob bounced from clinic to clinic, doctor to doctor, but he couldn’t seem to change his situation.

Then, in 2009, something in the back of Bob’s mind came to the fore when he attended a workshop sponsored by a legal clinic. They told him that he could apply for ODSP if he was sick. Bob didn’t think he was sick but he knew things were horribly wrong. He was not working and was still on welfare. The jobs and placements he was able to access were all dead ends.

Bob received a referral from the legal clinic to a mental health center, where he took a series of tests. After a period of time, the center came back with a diagnosis of bipolar disorder and post-traumatic stress disorder (PTSD).

Finally, this explained it. His application for ODSP went to the government and, after a wait of six months, was accepted. At this point, Bob was able to access more money because ODSP payments are over 70% higher than Ontario Works payments. He began to look after himself more. He ate better, went to therapy, was put on a drug treatment program, and began to understand how much his early experiences had affected him.

> Bob has always wanted to work but he knew that he would first need to find more stable housing. In 2011, he found the housing he required, enrolled in an employment program, and began to gain work experience.

The Rise of Disability Income Expenditures

Disability income expenditures are on the rise in Canada. In 2005,[5] total income support for Canadians with disabilities was estimated to be $23.2 billion. Five years later, in 2010, it was estimated to be $28.6 billion.[6] That’s an increase of 22.9%. (see Figs. 1 and 2).

A variety of factors are contributing to this overall increase. One of the most obvious is our **aging population**. We know, for example, that in 1971, the median age of Canadians was 26.2; in 2010, it was 39.7.[7] In 1971, Canadians aged 65 and older accounted for 8% of the population; in 2010, they accounted for just over 14%.[8]

There are many repercussions to an aging population in terms of providing appropriate support for people with disabilities. Extended lifespans for people with

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[5] In this paper, I refer to the Ontario and Canadian government fiscal year that runs from April 1 to March 31. Therefore, in this case, 2005 refers to fiscal April 1, 2005, to March 31, 2006.

[6] The original expenditure and survey data collected for this paper may be obtained by writing to the author at jsbb@rogers.com. The first data set includes administrative data and program costs compiled from publicly available expenditures on a program-by-program basis by researcher Anne Tweddle, which she aggregated for the purpose of this analysis. (See Annex 1 for primary sources and methodology.) A second original data set is also available that is based on survey data from Statistics Canada’s Longitudinal Assistance Database (LAD) for the purposes of verifying the direction of disability program expenditures over time.

[7] Anne Milan, Age and sex structure: Canada, provinces and territories, 2010, Component of Statistics.

Canada Catalogue no. 91-209-X, *Report on the Demographic Situation in Canada*. Pg 2. http://www.statcan.gc.ca/pub/91-209-x/2011001/article/11511-eng.pdf

[8] http://www4.hrsdc.gc.ca/.3ndic.1t.4r@-eng.jsp?iid=33

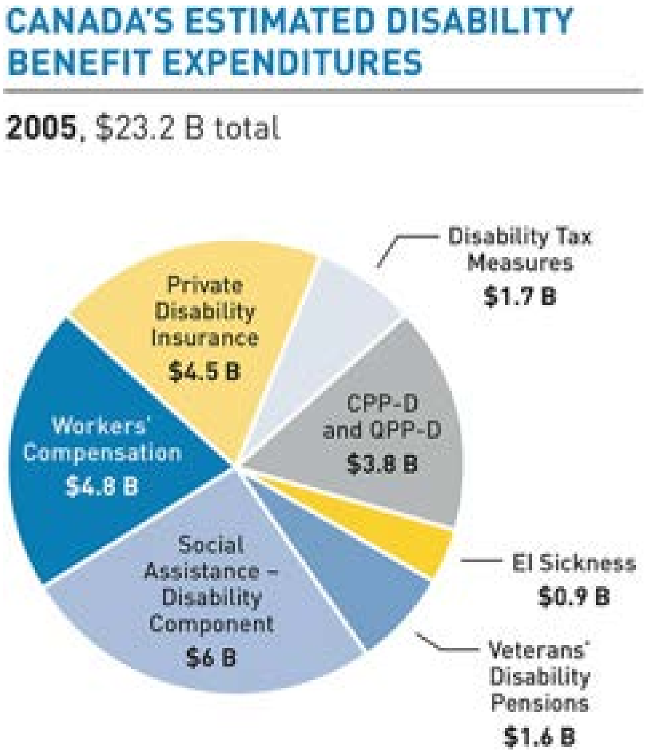

Fig. 1 Canada's estimated disability benefit expenditures

disabilities means that more Canadians are living longer with early-onset or birth disabilities. It also means that more Canadians are contracting late-onset disabilities.[9]

Another factor contributing to the growth of disability income expenditures is **continued difficulties people with disabilities face in accessing the workplace**. As noted by the Council of Canadians with Disabilities, among working-age people (15 to 64 years) living in poverty when the Participation and Activity Limitation Survey (PALS) was conducted, 48.4% of people without disabilities were employed compared with 23.1% of people with disabilities.[10]

There are also **growing numbers of people with disabilities living in poverty**. As the Council of Canadians with Disabilities points out, in 2006, the poverty rate for adult Canadians with disabilities was 14.4%. In terms of poverty among

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[9] http://disabilitystudies.ca/licproject/files/2011/07/ODI-Phase-1-Discussion-Paper-June-23.pdf

[10] Statistics Canada, *Participation and Activity Limitation Survey 2006: Labour Force Experience of People with Disabilities in Canada*.

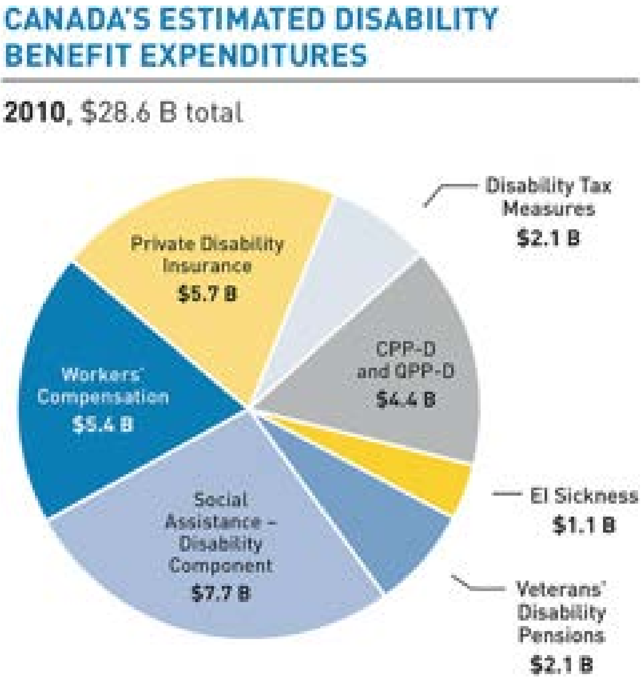

Fig. 2 Canada's estimated disability benefit expenditures

working-age people, the Conference Board of Canada recently ranked Canada in 15th place out of 17 countries and gave Canada a "D" rating.[11]

Another factor is the marked increase in Canadians seeking income support as a result of **more kinds of mental illness now being recognized**.[12] Mental disorders (psychoses, neuroses, and developmental delays) represented about 52% of the primary conditions of applicants granted ODSP in 2009.[13]

These external factors help explain the overall increased demand on our disability income system. But they don't account for the disproportionate increase of social assistance as a disability income support program; what I call the welfareization of disability incomes.

Canada-wide, social assistance has come to represent an increasingly large slice of the disability income support pie,[14] growing from $6 billion in 2005 to an

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[11] http://www.ccdonline.ca/en/socialpolicy/poverty-citizenship/demographic-profile/poverty-disability-canada and http://www.mowateitaskforce.ca/sites/default/files/Stapleton.pdf

[12] See *Brighter Prospects*, http://www.socialassistancereview.ca/uploads/File/COMM_Report_FinalH-t-Eng.pdf, Appendix F, p. 160–163.

[13] For example, ODSP growth in persons with neuroses and psychoses in 2011 was double the growth in the program overall.

[14] Expenditures exclude Registered Disability Savings Programs (RDSPs) due to their small size.

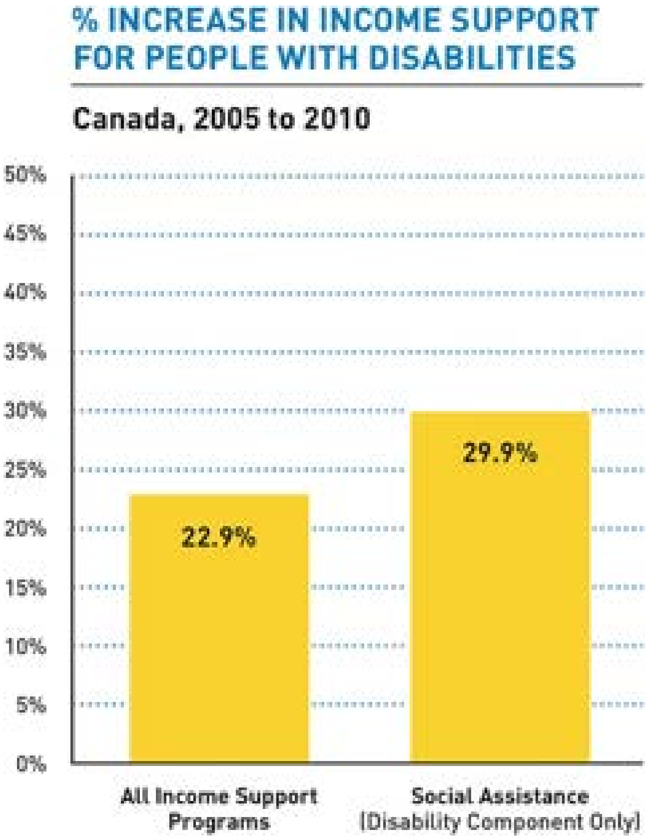

Fig. 3 % increase in income support for people with disabilities

estimated $7.7 billion in 2010. As a percentage, total income support for people with disabilities has increased by almost 23% over five years; social assistance disability spending increased by almost 30% (see Fig. 3).

The percentage increase in social assistance disability income program spending is most pronounced in Ontario (see Fig. 4). Total income support increased by 27.4%, while spending on ODSP increased 44.8%. Expenditures in 2011 totaled $3.8 billion.[15]

This means that in Ontario in 2010, ODSP comprised almost 30% of total disability income system expenditures. This was by far the highest percentage among the provinces examined and was a key area of concern for Ontario's recent social assistance review, *Brighter Prospects: Transforming Social Assistance in*

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[15] See *Brighter Prospects*, http://www.socialassistancereview.ca/uploads/File/COMM_Report_FinalH-t-Eng.pdf, p. 137.

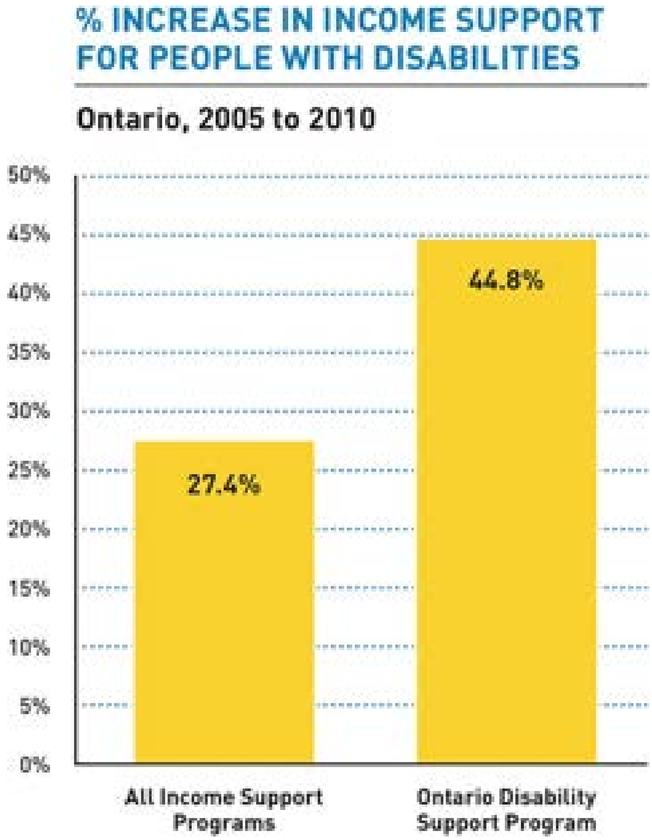

Fig. 4 % increase in income support for people with disabilities

Ontario.[16] In addition to being the largest percentage component, it is increasing at a disproportionately fast rate (see Fig. 5).

Ontario’s Disability Programs

Fifty years ago, in almost all instances, disability programs in Canada compensated persons because they could not work. The idea was to provide insurance against the hazard of disability. Most programs compensated an individual with a disability, but they didn’t focus on that person’s future.

Fundamentally, the large social insurance programs (CPP and EI), as well as private disability programs, continue to operate according to this insurance principle that views disability as a hazard that prevents workforce participation. When

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[16] Munir Sheikh and Frances Lankin, *Brighter Prospects*, 2012, Appendix F.

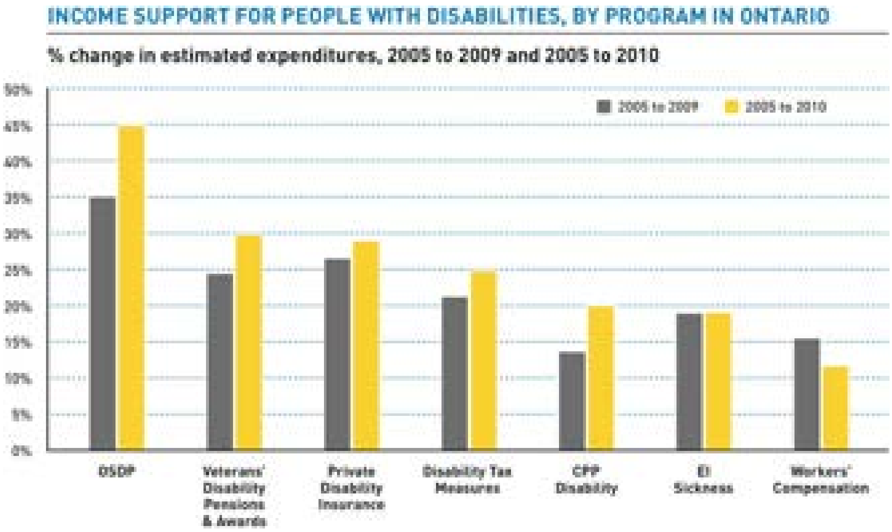

Fig. 5 Income support for people with disabilities, by program in Ontario

someone returns to work, the hazard is no longer present and therefore the insurance is no longer payable.

Since the 1980s, and especially with the publication in 1981 of the landmark *Obstacles* report,[17] we have wanted disability income programs that encourage persons with disabilities to work. We wish to compensate the person and find ways to accommodate the disability in favor of a future in work. However, there is little systematic movement to modernize and coordinate the programs with contemporary goals. This means we have a set of disability income systems that do not sit well beside each other. In Ontario, some set out to insist on a return to work (WSIB), some actually create disincentives to work (CPP-D), and one assists workplace re-entry with money, supports, and benefits (ODSP). They each have their own definitions of disability and their own terms of eligibility and benefit generosity. Taken as a system of benefits, they are not well coordinated and are focused more on individual program outcomes than client well-being.

It is in this context of real philosophical differences between programs, especially with respect to their disposition toward work, that we attempt to reframe the debate over why social assistance benefits for people with disabilities are changing. And, specifically, why ODSP is growing so fast.

The following is a description of disability income systems available to Ontario residents. Some are federally administered, some provincially. We'll look at them in order of overall size and significance.

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[17] http://www.cndd.ca/assets/research%20documents/Canadian%20Government/Obstacles%20-%20Can%20Govt.pdf

Ontario Disability Support Program

ODSP, as with social assistance programs in all provinces, provides benefits to persons with disabilities. In Ontario and in most provinces, eligibility is determined by a combination of the duration of disability and needs testing.[18] Disability status is established by a doctor’s certificate indicating the severity of disability. One notable exception is Alberta, where the Assured Income for the Severely Handicapped (AISH) program provides flat-rate benefits that are not needs tested in the traditional way.

ODSP benefits are over 70% higher than base welfare rates. Asset limits are also considerably higher. Work requirements are mandatory for basic social assistance, but there are no mandatory work requirements for persons with disabilities. Unlike most disability income systems, ODSP has no time limit. Employment supports and incentives are offered on an ongoing basis. Many critics have suggested that if the system’s superior incentive system could be integrated with the best aspects of a pension that does not impose strict needs testing or time limits, Canada could have the best possible disability income system.[19]

Ontario is the only province that pays First Nations people with disabilities through the provincial program. In other provinces Aboriginal Affairs and Northern Development Canada administers the program. However, based on separate First Nations numbers from these other provinces and a relatively small proportion of First Nations people in Ontario, this is most likely not a significant contributor to the rise in ODSP.

Over the past two decades, the benefit and asset limits under ODSP and its predecessor programs have steadily declined in real terms (to inflation).

Programs like the Special Diet Allowance have been reduced, while Community Start Up benefits have been pared. In 2005, basic income exemptions were cancelled (and only recently reinstated). Yet, throughout the course of this recent history, ODSP expenditure and caseload growth has accelerated (see Fig. 6), making it clear that program reductions and cuts have had little or no effect on caseload growth.

Private Disability Insurance

Most large employers offer employment-based short- and long-term disability (STD/LTD) plans. The share of premiums paid by the employer and employees varies widely.

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[18] http://openpolicyontario.com/wordpress/wp-content/uploads/2012/02/Understanding-Social-Assistance-Eligibility-Testing-in-Ontario.pdf

[19] http://openpolicyontario.com/wordpress/wp-content/uploads/2012/02/NavigatingtheMazeFinal.pdf. See, in particular, papers referenced in footnotes 12, 13, and 14

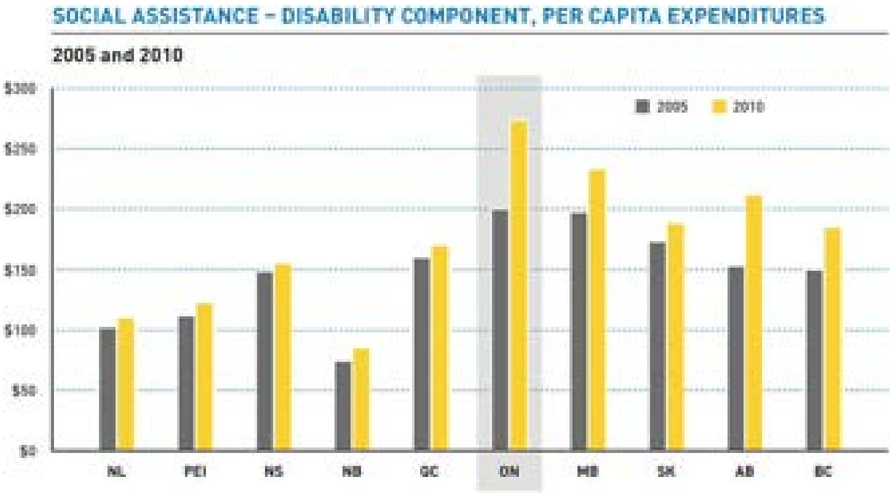

Fig. 6 Social assistance – disability component, per capita expenditures

Most plans provide a 2-year period of benefits for persons unable to perform their pre-disability occupation and who have medical evidence of a permanent or long-duration impairment. Thereafter, benefits are provided only if the beneficiary is unable to perform *any* occupation for which he or she is reasonably trained or educated.

Plan benefits are scheduled at 50% to 75% of pre-disability income. Benefits are reduced dollar-for-dollar by any CPP-D or workers' compensation benefits. Approximately 25% of all CPP-D insurance claimants have coverage from private disability insurance.[20]

Figure 7 illustrates that private disability insurance is growing in Canada on a per capita basis and has its strongest presence in Ontario. This increase suggests that changes to private disability insurance are not a strong contributor to the welfareization of disability incomes on an aggregate basis. Nevertheless, for persons like Angelica, loss of coverage through loss of employment status may be significant on an individual basis.

Workers' Compensation

Provincial workers' compensation agencies administer income security benefits for wage losses arising from disabling disease or injury caused by work exposures. The federal government also administers a workers' compensation program for federal employees. Employers pay the insurance premiums. The large majority of recipients

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[20] http://www.parl.gc.ca/Content/HOC/Committee/372/SPER/WebDoc/WD2169455/SPER372_CPPD_Issues/CPPD_IssuesPolitical_Pg03-e.htm

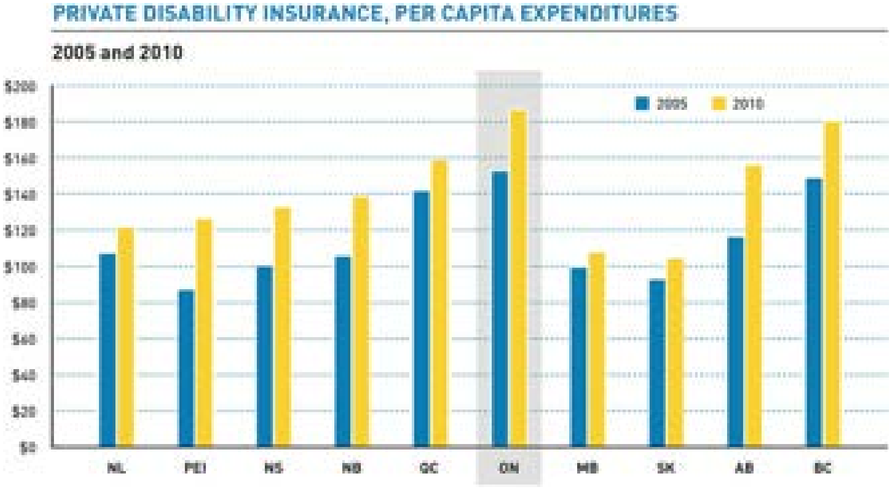

Fig. 7 Private disability insurance, per capita expenditures

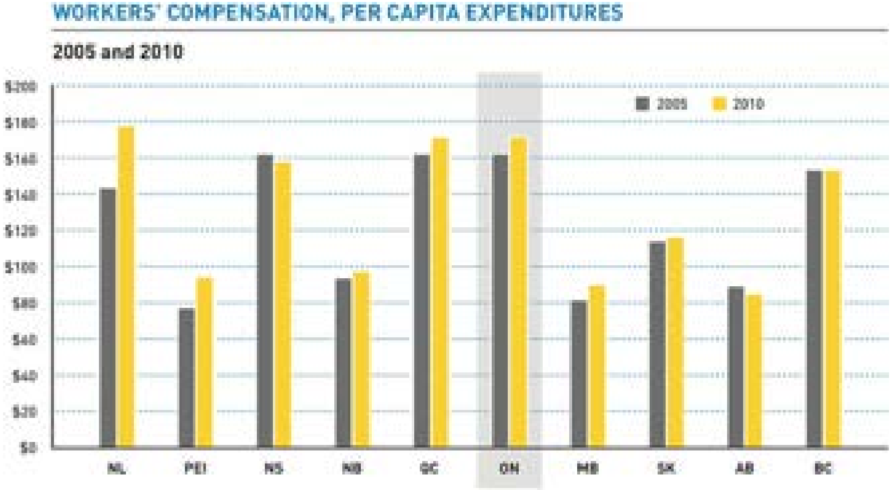

Fig. 8 Workers’ compensation, per capita expenditures

of provincial workers’ compensation wage replacement benefits experience temporary disability. However, provincial workers’ compensation agencies also administer benefits that acknowledge permanent impairment arising from a work-related injury or illness. Permanent partial disability benefits are payable to age 65. Benefit levels vary slightly among plans.

Figure 8 shows that workers’ compensation benefits, paid on a per capita basis, have been growing modestly and that Ontario is among the highest in expenditures. By 2010, Quebec, Ontario, and Newfoundland and Labrador continued to lead per capita spending, while the other provinces remain behind. It is worthy of note that changes to eligibility reducing WSIB benefits have been a matter of serious concern, especially in the post-2010 period.[21] These recent developments would appear to signal new pressures on ODSP.

Canada Pension Plan

The federally administered Canada Pension Plan is a compulsory contributory social insurance scheme. It provides income and protection in the event of retirement, disability, or death. Employers and employees contribute to CPP.

Eligibility for the Canada Pension Plan Disability program (CPP-D) is based on a stringent definition of disability: "severe and prolonged disability such that the person is incapable of gainful employment." CPP-D is treated as a "first- payer" by private long-term disability plans, provincial social assistance programs, and provincial workers' compensation agencies.

Confusion over the role of payroll taxes in Canada remains a serious concern, especially among immigrants. As CPP is contribution-based, only those who pay into the program through payroll taxes can receive CPP. Because programs like Old Age Security (OAS) and the Guaranteed Income Supplement (GIS) do not require contributions, the assumption is sometimes made that CPP is the same. In our first case example, Angelica did not fully realize the importance of not contributing once she became a contract worker.

The large differences in per capita payments between Atlantic provinces and Ontario (Fig. 9) cannot be explained by a prevalence of disability, demographics, or other factors. It may very well point to differences in appeal results in different parts of Canada. Lower per capita CPP payments are likely a major contributor to the welfareization of disability incomes in Ontario.

Veterans' Disability Pensions and Awards

Canadian Forces veterans, Merchant Navy veterans of the WWII or Korean War, current or former members of the regular or reserve force, and civilians who served in close support of the Armed Forces during wartime are eligible for a disability benefit administered by Veterans Affairs Canada (VAC).

Entitlement to a disability benefit is based on adjudication of the attribution of disability to exposures arising from service and the severity of disability. The disability benefit is reduced if the recipient is receiving benefits from an employment-based group disability insurance plan.

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[21] National Union of Public and General Employees (NUPGE), Injured workers protest WSIB cuts: KPMG recommends cuts to workers' compensation benefits http://www.nupge.ca/content/4706/injured-workers-protest-wsib-cuts-kpmg-recommends-cuts-workers-compensation-benefits

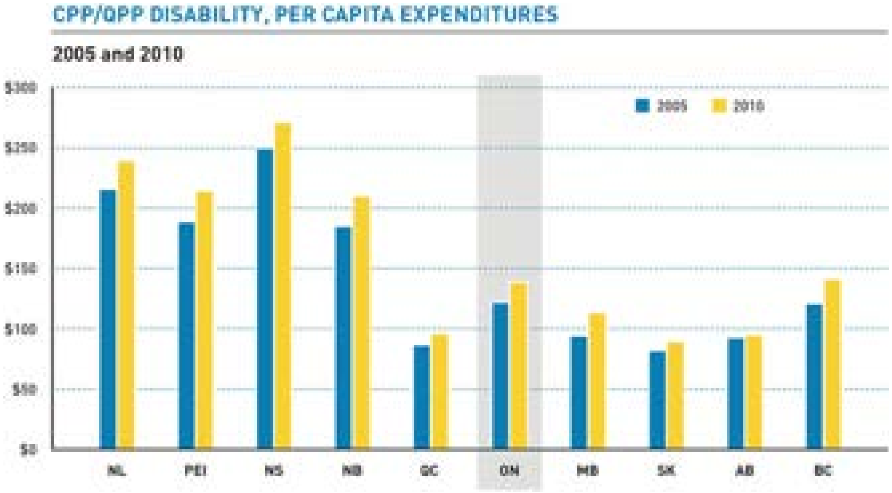

Fig. 9 CPP/QPP disability, per capita expenditures
Note: Quebec administers the Quebec Pension Plan. A digest of differences between CPP and QPP is available in a useful article by Canadian Payroll Consulting. (Canadian Payroll Consulting, Recent changes increase the differences between CPP and QPP, June 2012, http://alanrmcewen.com/2012/06/20/recent-changes-increase-the-differences-between-cpp- and-qpp/)

Pursuant to the *New Veterans Charter*, which came into force on April 1, 2006, disabled veterans are eligible for a disability award. This may be paid as a lump sum, as an annual payment, or as a combination of the two. Veterans' disability benefits have increased significantly in the new millennium due to two factors. One is Canada's enhanced military role (e.g., Afghanistan). The other is the increased recognition of trauma (post-traumatic stress disorder) as a disabling condition. Prior to 2006, eligible military veterans received ongoing pensions from VAC. With the conversion of some pension entitlements to lump sum payments, once the lump sum payment is spent, many veterans may be applying for social assistance disability programs.

It's uncertain what's causing the lower per capita payments in Quebec, Ontario, and western provinces – it may reflect differences in appeal results – but, like CPP-D, what is certain is that they put pressure on social assistance disability programs in these provinces. Veterans who have less access to military pensions are faced with the need to access social assistance to meet their ongoing needs (see Fig. 10).

Employment Insurance Sickness Benefit

The EI sickness benefit is administered by the federal government. It provides benefits for temporary disabilities for up to 15 weeks. To qualify, the worker must demonstrate that regular weekly earnings have decreased more than 40% due to

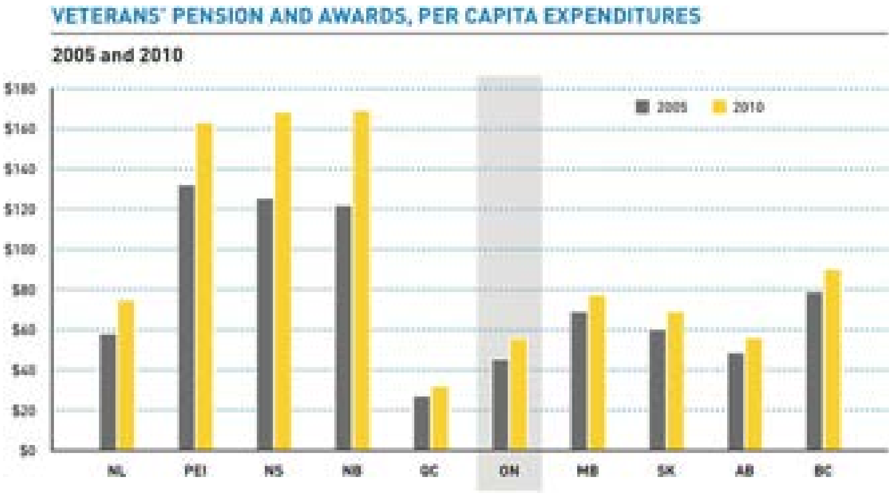

Fig. 10 Veterans' pension and awards, per capita expenditures

disability and that 600 insured hours have accumulated over the previous 52 weeks or since the worker's last claim.

The basic benefit rate for EI sickness is 55% of a worker's average insured earnings, up to a yearly maximum insurable amount. Employment insurance sickness benefits are administered as a "last-payer" program. Benefits are reduced when beneficiaries receive benefits from workers' compensation, group insurance income, and accident compensation for lost wages.

EI sickness benefits per capita are far higher in the Atlantic provinces than in the rest of Canada. This likely is a significant reason why the Atlantic provinces have a more moderate growth in their social assistance programs for persons with disabilities (see Fig. 11).

Tax Measures

Disability Tax Credits

The Disability Tax Credit (DTC) is administered by the Canada Revenue Agency under the *Income Tax Act*. It is non-refundable and is available to persons who are blind, are receiving life-sustaining therapy, or who have an impairment of physical or mental functions that has lasted or is expected to last one year. These non-refundable tax credits are used to reduce the amount that the person owes on federal income tax.[22]

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[22] Other tax measures include the medical expense tax credit, caregiver credit, infirm dependent credit, disability supports deduction, and the refundable medical expense supplement. Some of these tax measures are available to people without disabilities who have qualifying medical expenses.

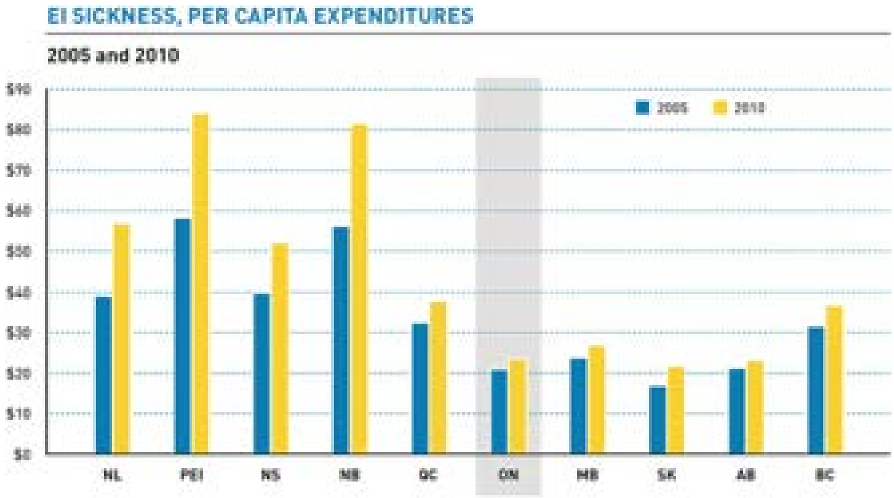

Fig. 11 EI sickness, per capita expenditures

In rare instances, social assistance recipients may have sufficient taxable income to benefit from the DTC, but in most instances the DTC benefits persons with disabilities who would otherwise be paying income tax. Social assistance itself is non-taxable, but other benefits like CPP and EI are taxable. The more tax payable, the more the DTC is worth.

Registered Disability Savings Plan

The registered disability savings plan (RDSP), established in December 2008, is delivered by the Canada Revenue Agency. Canadians who are eligible for a DTC and are under 60 years of age are eligible to open a RDSP. The RDSP includes a matching government grant and a savings bond. The lifetime contribution limit is $200,000 and there is no annual limit. Contributions are not tax-deductible and are not included in income when paid out of an RDSP.

Investment income accumulates tax-free but is included in the beneficiary's income for tax purposes when paid out.

Although a significant expenditure, these tax measures have no effect one way or the other on the rise of ODSP.

Ontario's Disability Programs: What Can We Conclude?

The increase of ODSP expenditures is a complex issue. Of the many intricate factors causing the spike in ODSP, I believe the most significant one is the current labor market. It has become precarious with an increase in part-time, temporary, and contract work. Fewer people in stable salary and wage jobs means that employer-triggered disability income systems have fewer wage and salaried employees to support while they tighten eligibility requirements for their services. This is especially true for workers' compensation.[23]

A significant number of individuals with disabilities are discovering that they are not eligible for employer-triggered disability income programs – private insurance, workers' compensation, CPP-D, veterans' disability, and EI sickness. And many who are eligible for employer-triggered disability income programs exhaust their benefits. Once their savings and assets are depleted, ODSP becomes the only possible income support program.

It's important to note that when employer-triggered programs are available, they are limited in their efforts and ability to help people return to work. This is documented in the CPP study: *Wrestling With the Poor Cousin: Canada Pension Plan Disability Policy and Practice, 1964–2001*.[24]

In the past, employer-triggered disability income programs were expected to provide the supports required in the disability income arena. They were designed to do the "heavy lifting" by compensating the loss of income due to an inability or incapacity to work. Social assistance, on the other hand, was not designed to be a disability income program; it was designed to provide support to low-income people living with disabilities and, wherever possible, compensate efforts made to secure employment. However, changing relationships between employers and employees combined with cuts in access and new tougher rules in some disability income systems – especially the employer-triggered ones – is expediting a shift of disability expenditures to the public purse.

In addition to cuts in many employer-triggered programs, tighter eligibility rules in OAS and GIS for immigrant seniors are also contributing to a rise in ODSP. OAS and GIS combined usually exceed the amounts paid by ODSP, meaning that seniors are not eligible for ODSP. However, a growing number of seniors (immigrants and persons returning to Canada) cannot access full OAS because they do not meet Canadian residency requirements. In these situations, seniors with disabilities may be eligible for a social assistance top-up.

Statistics Canada's Longitudinal Assistance Database (LAD) provides Canada-wide information about program usage and overlap. If we use the database to compare the period between 1992 and 2009, it shows that the proportion of the population receiving workers' compensation has declined steadily. The workers' compensation figures are particularly troublesome, showing a decrease from 4.2% in 1992 to 2.4% in 2009. Conversely, the proportion of the population receiving CPP/QPP disability benefits or claiming the disability tax credit has been increasing steadily since 2000.

Over this 17-year period, the proportion of the population receiving social assistance who were also receiving other CPP-D/QPP-D benefits has more than

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[23] *2012–2016 Strategic Plan: Measuring Results*. Workplace Safety & Insurance Board, August 8, 2012, p.14. http://www.wsib.on.ca/files/Content/MeasuresReportsQ22012MeasuresReport/Corporate%20MeasuresQ22012.pdf

[24] http://books.google.ca/books/about/Wrestling_with_the_Poor_Cousin.html?id=yc5jQwAACAAJ&redir_esc=y

doubled – increasing from just under 2% to nearly 5%. Similarly, the proportion of social assistance recipients receiving one or more of CPP-D/QPP-D or workers’ compensation increased from 5% to over 10%. It is worth noting that in Ontario, the number of ODSP recipients who also receive CPP-D totals more than 30,000.

This means, in part, that more people with disabilities are not able to fulfill their income security requirements through other programs and, eventually, become eligible for social assistance. In other words, increases in CPP and ODSP are not inconsistent. With reduced labor force attachment in general, many more people with disabilities access lower amounts of CPP while the aggregate number of recipients continues to increase. In any instance where CPP benefits (based on contribution) fall below the benefits available through ODSP, the CPP recipient becomes eligible for a top-up from ODSP and aggregate numbers of recipients increase over the same time period.

Although the increasing demand on ODSP is problematic in terms of benefit adequacy, ODSP is providing a critical safety net. For persons with disabilities it is the only system with neither time limits nor specific previous work requirements. As such, its emphasis on providing workplace and employment supports, along with structural incentives to work without threat of disentitlement, provides an important model for the future redesign of disability income programs.

Regional Variations

Outside of Ontario, social assistance disability expenditures are rising fastest in Alberta and British Columbia, followed by Manitoba (see Fig. 12). In these provinces, other disability income support program expenditures are not increasing at the same rate.

One regional variation that may not account for significant numbers but is worth noting is that Ontario and the four western provinces have larger Aboriginal populations. In 2011, First Nations Social Assistance for people with disabilities accounted for 11.4% of total spending in both Manitoba and Saskatchewan. By contrast, in New Brunswick, spending on First Nations Social Assistance for people with disabilities amounted to 3.4%. This was the highest amount of any of the eastern provinces.

Another distinguishing factor of Ontario, Alberta, and British Columbia is their high rate of urbanization.[25] We know that big cities have much higher levels of part-time and temporary employment, and lower levels of full-time and permanent wage and salaried positions.[26] By extension, it is highly likely that these provinces also have a smaller portion of people with disabilities in the mainstream workforce.

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[25] http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/demo62n-eng.htm

[26] Based on StatCan data from 2001 and 2003 and from the *Survey of Income and Labour Dynamics.*

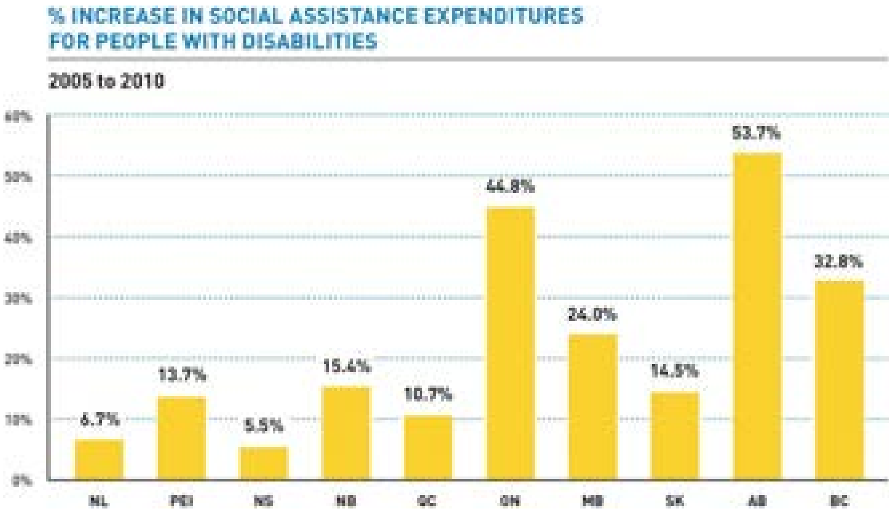

Fig. 12 % increase in social assistance expenditures for people with disabilities
Note: Alberta shows the highest rate of growth. This is largely explained by the generosity of design and benefits in the Assured Income for the Severely Handicapped (AISH) program

The fact that Canada's biggest cities are in provinces that have fewer full-time permanent jobs shows a correlation with higher social assistance disability incidence (especially in Ontario, with Toronto, and in B.C., with Vancouver). The correlation is relevant, as persons with disabilities have a demonstrated lower access to full-time permanent jobs.

Urbanization may account for several other factors that Ontario, Alberta, and British Columbia have in common, including lower per capita access to employer-triggered disability systems and more generous social assistance programs.

Access and Eligibility to Employer-Triggered Disability Income Systems

Ontario and provinces westward have lower per capita coverage from employer-triggered disability income systems. This may relate to fewer workers being in the regular workforce in more urbanized centers. For example, EI regular payments provide stronger coverage in Quebec and eastward versus Ontario and provinces to the west (see Fig. 13).

Generosity of Programs

Ontario, Saskatchewan, Alberta, and British Columbia all have demonstrably larger, more generous, separate social assistance programs for people with disabilities. In all

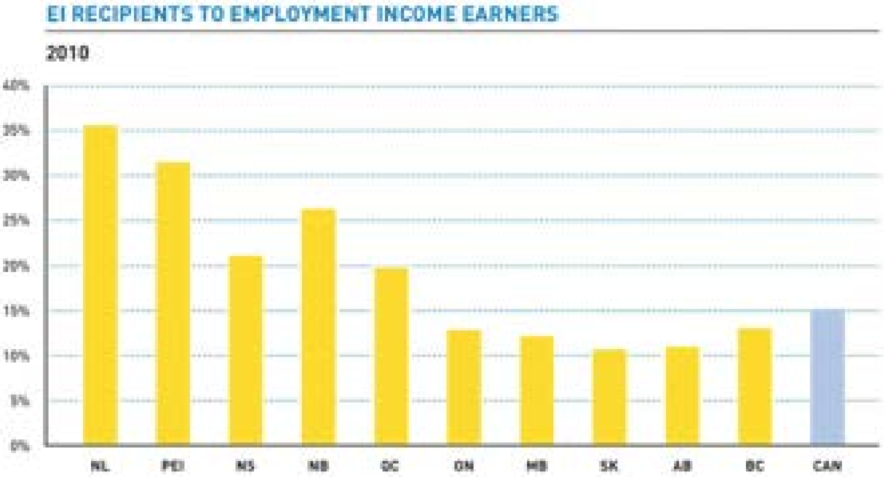

Fig. 13 EI recipients to employment income earners

other provinces, benefits for people with disabilities are provided through the existing social assistance legislation.[27]

In previous research I conducted,[28] it was demonstrated that the effects of the recession of 2008–09 on the number of social assistance recipients were markedly different in Ontario and the western provinces than in Quebec and the eastern provinces. Social assistance caseloads in the eastern provinces had returned to pre-recession levels, but in Ontario and the western provinces they were up an average of 23%. It may be the case that regular EI availability (in addition to EI sickness benefits) plays an important role in reducing social assistance disability benefits in Eastern Canada. As Fig. 14 shows, EI per capita claims are much higher in the Atlantic provinces. As EI keeps people from applying for social assistance, social assistance caseloads are more modest in the Atlantic provinces. There is a strong correlation between higher EI caseloads and lower social assistance caseloads.

The asymmetry of regular EI benefits across Canada (Fig. 14) is widely acknowledged. It is less well known that three other major income security programs – CPP-D, veterans’ benefits, and EI sickness – share this same asymmetry (Refer to Figs. 9, 10, and 11). More generous CPP-D, veterans’ benefits, and EI sickness in the Atlantic provinces may help explain why the increase in social assistance disability benefits has not happened there.

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[27] The legislation may provide for distinct program streams for different types of clients.

[28] http://www.mowateitaskforce.ca/sites/default/files/Stapleton.pdf

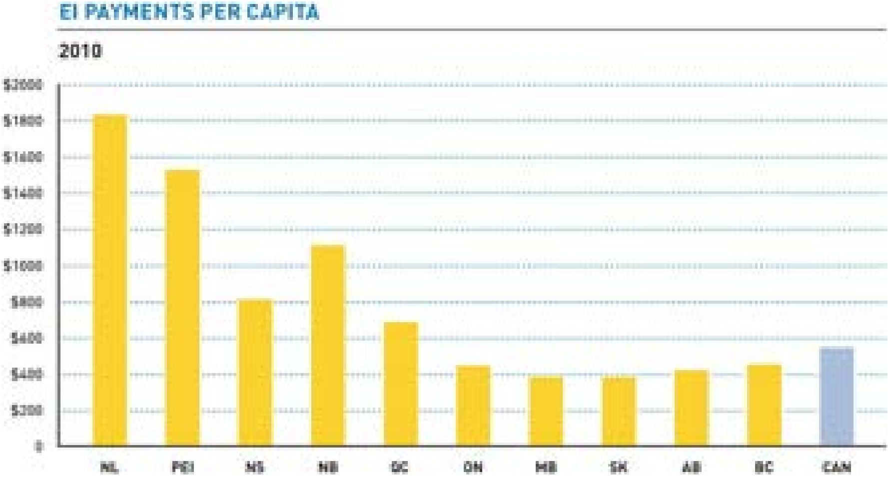

Fig. 14 EI payments per capita

Consequences of Current Trends

If this startling increase in social assistance disability expenditures in Ontario (and other large urbanized provinces) continues, along with the shift from employee-based programs to the public purse, it will likely have serious consequences for beneficiaries of the various income support systems and the governments providing these benefits.

Reasons to be concerned include the fact that the changes we have noted here constitute the development of social policy by default. No government nor any group within civil society or the private sector sat down and set these policy directions in advance. As such, they have evolved based on unintended consequences of various changes that have taken place.

It may be the case that governments, civil society, and the private sector don’t fully understand the consequences of reducing overall expenditures of, and the number of clients in, disability income systems other than social assistance. It is also likely that they do not see increases in social assistance disability expenditures as a natural “hydraulic” reaction to the erosion of stable jobs and subsequent reductions in growth of employer-triggered disability income programs.

The perception remains that if you are active in the labor market you have systems at your disposal to support you in dealing with a disability. There is also an important message here for workers who do not have disabilities – particularly contract and part-time workers. The message is that whether or not you are an active member of the work force, if you do not have payroll deductions or pay into a private disability plan, you are not protected against the hazard of future disability and you risk looking to ODSP as the only option for an ongoing stable, but low, income.

As noted earlier, one advantage of ODSP carrying a larger load is that social assistance permits a recipient to work and receive benefits. Unlike employer-triggered programs, there is no automatic cut-off when a recipient engages in paid employment. For this critical reason alone, there is a case to be made that other disability income systems should consider aligning themselves more closely with approaches taken by social assistance. In addition, social assistance benefits are statutory, not time limited (except once the recipient reaches age 65), and often come with good ancillary benefits such as medical transportation, disability-related supplies, and dental care. It is important to note that most other disability income programs do not provide similar benefits.

It is also important to be cognizant that the amount of money an ODSP recipient receives is less than the support he or she would receive from an employer-triggered program. Also, income from other sources is deducted from social assistance payments. In addition, social assistance imposes limits on the assets recipients are allowed, so those receiving social assistance disability income supports generally have limited means. Finally, social assistance itself is stigmatized.

This trend is definitely not free of consequences and more research is required to understand the ramifications and to ascertain whether it is good social policy to increase the prominence and the role of social assistance as the single largest source of disability income. Appendices A and B list a number of topics for further research and potential sources of data for this research.

Closing Thoughts

In this chapter, I have presented possible reasons why the Ontario Disability Support Program is growing so fast. I have proposed that the driving force behind this trend is changes that are occurring within the labor market. These changes mean an increase in the number of individuals who are no longer able to qualify for or access employer-triggered disability income programs, despite the fact that many of these people – such as Angelica – have a history of continuous work. This results in a **shift of coverage and responsibility from employee-based disability income programs to the public purse in the form of social assistance**.

It is beyond the scope of this chapter to conclusively verify this hypothesis. Instead, I have outlined what I believe to be the most significant factors at play. Ultimately, I hope that future research will enable us to understand more thoroughly the causes and consequences of the welfareization of disability. In turn, this will enable policy-makers to provide more effective, robust, and humane support to Ontarians and Canadians with disabilities.

Given the complexity of our disability income systems, changes to programs that are done in isolation will not necessarily create the desired result. For example, the Ontario government may follow some of the recommendations in *Brighter Prospects* to achieve savings through reduced caseloads or more modest caseload growth. But putting new strictures on ODSP in order to achieve savings and slow the increase in caseloads is unlikely to be successful, as the reasons ODSP is growing have little to do with rates, rules, or policies. This can be illustrated clearly through the example of our case studies. The reasons that Angelica and Bob are applying to ODSP relate entirely to changes that are outside of the purview of ODSP rules: changes in the social, medical, economic, and labor market environments in which ODSP operates today.

What both Angelica and Bob have in common is that they are each likely to receive social assistance disability income benefits that would not have been paid a short generation earlier. Both Angelica and Bob have needed to turn to ODSP because there is no other program that can provide them with the assistance they need. Bob, and Angelica if her application is approved, will receive ODSP without any internal changes to ODSP itself.

The lesson for policymakers is that any impulse to change program rules in order to bring caseloads down may not have the desired effect, since the reasons that Angelica and Bob applied to ODSP have nothing to do with those rules.

Given the complexity of disability income systems, it is clear that they cannot be understood in isolation from each other. What I have tried to do in this paper is frame the social assistance disability income system within the context of all eight disability programs operating in Ontario in order to gain a clearer understanding of what is going on – how they are growing and moving as one single, interconnected system. Only in this way does the growth of social assistance begin to be meaningful and understandable. Only then does it become clear that many of the reasons for its extraordinary growth are external to itself.

The challenge we face in trying to find a way to transform our disability income systems is that **programs have widely varying purposes**, they are administered at various levels of government and the private sector, they are funded differently through income and payroll taxes or employer levies, and they have vastly varying governance structures that together produce a wave of haphazard gaps, overlaps, and unintended consequences.

Disability income programs vary widely on the issue of workforce participation. Some programs encourage or insist on workforce participation or return to work, while others reduce or end coverage once workforce participation begins. **Social assistance, as a system that encourages work, is often stymied by other disability income systems** that stop coverage when a person participates in significant work or if they believe the person has not tried hard enough to return to work.

Some programs have benefits that are time-limited, others have benefits that are limited to particular interventions, and others have benefits that are permanent. Two of the programs (EI and CPP) are in place because of constitutional amendments undertaken many decades ago. Both programs would require multilateral discussions between the federal government and the provinces in order to effect reform.

Clearly, if there was an opportunity to start from scratch, no one would ever devise the array of disability income programs that currently exists. Neither individually nor as a collective set of systems do they begin to meet the real needs and expectations of people with disabilities. So, how do we find our way forward to transform the convoluted quagmire of eight very different disability income systems? Although opportunities to mount this discussion are limited at best, there is a desperate need for reform.

Any changes made to disability income programs require careful consideration of the whole system and I believe this is our best starting point. Should all parties agree to the creation of just one more commission dedicated to the task of disability income system transformation and supported by all levels of government and private and non-profit sectors, there would be reason to be optimistic that there is a way forward to a coherent set of policies that could guide us through a successful transformation.

Conclusion

Our income security system in Canada is inadequate as it relates to the poor and many parts of it are confusing, outmoded, and unfair. But that does not make it a terrible system. In many ways, it reflects our culture and much that is good within it. We need to be very careful about what we dismantle or allow to disappear inadvertently.

Old Age Security, the Guaranteed Income Supplement, our new child benefit system, CPP and EI are very good programs that – with a little bit of redesign work – could take vast swaths of people out of poverty. There is no good reason to throw them out and every reason to build enhancements using them as key building blocks of a new system.

Carl Jung said in his famous defense of astrology:

> We are born at a given moment in a given place and like vintage years of wine we have the qualities of the year and of the season in which we are born. Astrology does not lay claim to anything else.[29]

Our income security programs that pay out over $200 billion a year (much more during the pandemic) all bear the earmarks of their vintage. The beginning era of modern social assistance in Canada spanned from 1916 to 1939. Social insurance’ beginnings (in Canada) span the 26 years from 1940 to 1966. Old Age and disability pensions began in 1927 and took their present form at the end of the 1960s. The era of refundable tax credits began at the federal level in 1978 and continues to this day. Pandemic benefits reflect their obvious relationship to infection, illness, death, and recovery. Much of our system is now settled in place well beyond their eras of invention. This history is both remarkable and important.[30]

Still, to many, our present income security system can look like a couple of dozen cats in a bag. To a young person it must look like a horrible hodge-podge of divergent efforts mummified by Band-Aids. But as Wade Davis said, our system, like our culture is:

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[29] http://www.wisdom-of-astrology.com/thewisdomofastrology%3Ayourlife'sblueprint

[30] The Covid19 pandemic and the unprecedented addition and withdrawal of pandemic benefits froze -for a moment in time- the welfareization process. It is likely to continue as there have been no fundamental changes to income security immediately following the pandemic.

> . . .a vast archive of knowledge and expertise, a catalogue of the imagination, an oral and written language composed of the memories of countless elders and healers. . .[31]

Throughout the history of man, there have been countless movements to fix the burden of an unsatisfactory present with a clean slate, a “tabula rasa.” “Starting over” appeals to an element within the human spirit – it is neither right nor wrong.

Tinkering and fixing things with “chicken wire and glue” is equally an element of our humanity. Most of us admire the 1950s cars in Cuba that still run with hundreds of reengineered parts and workarounds. The point is that they still work. “Clean slaters” and “fixer/tinkerers” each have their own place in the annals of reform and depending on the problem at hand, they are equally revered or reviled.

In all of the discussions of a guaranteed annual income or basic income over the years, many have said that Canada could start with a basic income for people with disabilities. In my report for the Metcalf Foundation called the Welfareization of Disability Incomes in Ontario, I said the following:

> Clearly, if there was an opportunity to start from scratch, no one would ever devise the array of disability income programs that currently exists. Neither individually nor as a collective set of systems do they begin to meet the real needs and expectations of people with disabilities. So, how do we find our way forward to transform the convoluted quagmire of ten large very different disability income systems? Although opportunities to mount this discussion are limited at best, there is a desperate need for reform.[32]

It would seem a lot easier to mount a basic income for people with disabilities for two reasons:

1. It is cheaper – $12 billion nationally as opposed to $50 billion + for everyone.
2. Few are worried about work *requirements* for people with disabilities – in other words, the public would not worry that people with disabilities should be forced to work to obtain income assistance in the same way they worry about people without disabilities.

So, with those two great policy and public opinion advantages, why is it so hard to take a logical first step toward a basic income by ushering in a basic income for people with disabilities?

Before answering the question, let’s look at all the expenditures made in Canada under our various income programs. There are ten large separate disability income systems in Canada depending on who is counting. They spend over $40 billion a year in transfers to individuals:

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[31] Wade Davis, The Wayfinders – Why ancient wisdom matters in the modern world – CBC Massey Lectures- 2009, House of Anansi Press, page 34.

[32] http://metcalffoundation.com/wp-content/uploads/2013/12/Welfareization-of-Disability-Incomes-in-Ontario.pdf p.30 – updated 2021.

- Private disability accident insurance
- The Registered Disability Savings Plan (RDSP)
- The Canada Workers Benefit for people with disabilities
- Social assistance
- Workers' Compensation
- The Disability Tax Credit
- Veterans' programs
- Private programs
- CPP – Disability
- EI sickness

The reality is that it is not simpler to implement a basic income for people with disabilities. In fact, it would be harder. The Disability income system would be much more difficult to reform than the systems for either seniors or children. In addition:

- Eight of the ten systems pay benefits to people who are not poor. Only social assistance and the CWB-D have specific rules that direct payments to low-income people with disabilities.
- Four of the programs/systems pay temporary benefits only – they are not designed to pay long term benefits, i.e.,
  - EI Sickness – 26 weeks.
  - Workers' Compensation – generally up to two years.
  - Private programs – generally up to two years.
  - Veterans' program – only permanent for WWII and Korea veterans.
- The programs that are paid to low-income people with disabilities are not indexed and are inadequate (i.e., social assistance and the CWB-D).
- Six of the ten disability income programs can only be accessed through previous or current employment.
- Two of the ten programs (EI and CPP) are subject to Constitutional protections.
- The most inadequate program (social assistance) is increasing its share of overall expenditures on people with disabilities.

In sum, Canada has an overall disability income system paying out more than $40 billion in benefits that:

- Is largely not directed (by design) to low-income people.
- Pays only temporary benefits under half of its programs.
- Is largely inadequate and only partially indexed.
- Exhibits a growing "market share" represented by inadequate social assistance benefits.
- Is largely based on previous or current employment.
- Is Constitutionally entangled.

Accordingly, it would be no easier to mount a basic income for persons with disabilities than any other subset of the population. Nevertheless, with a

$40 billion base and with political will, it would be far easier to disentangle current programs.

This is the way I ended my paper on the Welfareization of disability benefits:

> Any changes made to disability income programs require careful consideration of the whole system and I believe this is our best starting point. Should all parties agree to the creation of just one more commission dedicated to the task of disability income system transformation and supported by all levels of government and private and non-profit sectors, there would be reason to be optimistic that there is a way forward to a coherent set of policies that could guide us through a successful transformation.[33]

We await the process and the new design ten years later.

Appendix A: Other Research Topics

The following research topics could shed light on possible reasons why employer-triggered programs are not "pulling their weight." These may provide further explanation in answer to the question of why social assistance is becoming the dominant income system. These alternative hypotheses also require additional research.

Job Security

A hypothesis very much intertwined with our original hypothesis is that the deterioration of traditional employment is steering increasing numbers of people with disabilities away from employer-triggered income support programs.

Additional research should examine the experience of people with disabilities with non-traditional employment.

Lack of Knowledge

An alternative hypothesis is that some regularly employed individuals with disabilities may not be aware that they are eligible for employer-triggered supports. They may turn to social assistance as a more familiar form of income support. Further research should test employees' knowledge of various income support programs for people with disabilities.

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[33] http://metcalffoundation.com/wp-content/uploads/2013/12/Welfareization-of-Disability-Incomes-in-Ontario.pdf p.30

Economic Recession and Workplace Injury

Another hypothesis is that workers' compensation expenditures are lower during a recession, boosting the relative importance of other income supports, including social assistance. The theory is that less experienced workers are more likely to get hurt on the job but are also the first to be laid off in a recession. As they are laid off, workplace injury rates and overall workers' compensation expenditures decline. In addition, an economic recession inhibits job-seeking efforts of those on claim to get re-employed, so they are eventually funneled into social assistance.

Additional research is required to understand the interplay between economic conditions, workplace injury, and access to employer-triggered supports.

Time Limits/Accelerated Decay of Benefits

Another hypothesis is that the workers' compensation benefits share of total disability income support expenditures is declining because employers have a financial incentive to bring injured workers back to work. The experience rating process ties the premiums employers pay for workers' compensation to actual reported losses. The longer an employee receives workers' compensation benefits, the larger the increase in the employer's premiums. The possible result of this financial incentive is that employers work harder to bring injured workers back to work.

Further research is required to understand the effects of the various incentives on employer behavior and the ultimate rates of reintegration of people with disabilities into the workplace.

An alternative hypothesis relating to workers' compensation addresses fiscal pressures associated with long-duration disability episodes. Ten percent of people receiving workers' compensation benefits are offered retraining/employment assistance programming. Once these avenues are exhausted, they can be deemed unemployable. For example, 30% of the flow into B.C.'s social assistance disability benefit program is of people who used to be receiving workers' compensation benefits.

Disability Culture

The disability culture hypothesis focuses on choice, positing that individuals will choose to access social assistance disability benefits over retaining work or accessing other benefits.

Further research is necessary to investigate this theory. Are individuals choosing not to work and marshaling existing impediments in such a way as to obtain disability benefits? Are individuals who do not believe they have a reasonable opportunity to work marshaling these impediments in this way because disability benefits are greater than regular social assistance benefits? In Ontario, for example, disability benefits on ODSP are over 70% higher than regular Ontario Works social assistance benefits. Benefits for a single disabled person in British Columbia are almost 50% higher than regular social assistance benefits.

An additional factor to consider is the other perceived benefits of social assistance support. For example, a recipient of social assistance may still work sporadically. The recipient would also be eligible for health benefits not provided by other programs. Social assistance programs also frequently provide rapid reinstatement for people with disabilities who try to exit.

One issue to explore is the labor force participation of people with disabilities. How and to what extent are people with disabilities participating in the labor force? How and to what extent are they engaged in non-traditional work, making them ineligible for employer-triggered supports? Statistic Canada's Participation and Activity Limitation Survey provides some data about labor force participation:

> According to the Participation and Activity Limitation Survey (Statistics Canada, 2008b), 2,457,350 persons with disabilities between the ages of 15 and 64 could have participated in the labour force. Of this group, 51.3% were employed, 43.9% were not in the labour force, and 4.9% were unemployed. In contrast, among those without disabilities, 75.0% were employed, 20.0% were not in the labour force, and 5.0% were unemployed.
>
> The unemployment rate was 10.4% for persons with disabilities, compared to 6.8% for the population without disabilities.[34]

Another question addresses the demographics of those benefiting from social assistance disability income programs versus those benefiting from the employer-triggered programs. It will be important to explore the extent to which individuals are accessing multiple benefits and how this affects total income support received.

Appendix B: Data Sources for Further Research

Data Sources Relating to Demographics and Labor Market Participation of People with Disabilities

The **Longitudinal Administrative Databank (LAD)** comprises a 20% sample of the annual T1 Family File provided to the Canada Revenue Agency. It contains demographic information and income information about labor market participants, including amount of labor market earnings and income from other sources.

The **Survey of Labor and Income Dynamics (SLID)** provides longitudinal data on more than 30,000 Canadian households. Two panels of households are surveyed for six consecutive years, answering the same questions. One limitation of this source is that it provides data on disability, but not workplace disability specifically.

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[34] The Centre for Addiction and Mental Health, *The Aspiring Workforce: Employment and Income for People with Serious Mental Illness*, pg. 87.

The **Participation and Activity Limitation Survey (PALS)** contains useful data on people living with activity limitations. However, the last survey was conducted in 2006, which may make the data not useable.

Data Sources Relating to Disability Expenditures

Statistics Canada provides data on disability expenditures in a variety of sources. No single source can provide all the data needed, but information from several sources can help confirm the trends identified.

The LAD provides data on disability tax credits, CPP-D, workers’ compensation, and social assistance from 1992 to 2009. It can also follow people with disabilities over time, enabling an analysis of, for example, the duration of individuals’ use of disability deductions/credits. However, the LAD does not distinguish between regular EI benefits and EI sickness benefits. A significant limitation is that it cannot identify people with disabilities unless they are receiving disability tax credits, CPP-D, workers’ compensation, and/or social assistance.

As for veterans’ pensions, no information can be found in tax data or on SLID.

Annex 1: Disability Spending in Canada, Primary Data Sources and Methodology

Income support category	Data source(s)	Methodology
Disability Tax Measures	Dept. of Finance Tax Expenditure Report for all measures except the Child Disability Benefit http://www.fin.gc.ca/taxexp--depfisc/2011/taxexp1101--eng.asp#toc6 Office on Disability Issues annual report, appendices for Child Disability Benefit. http://www.hrsdc.gc.ca/eng/disability_issues/reports/fdr/2010/fdr_2010.pdf	Provincial data not available. Data have been estimated using the federal amounts multiplied by each province’s estimated percentage of the total population
CPP Disability	HRSDC – OAS and CPP Statistics book for national data HRSDC – ISP monthly statistical bulletin for provincial data (Reports available by request from HRSDC)	Net benefits paid by fiscal year
QPP Disability	HRSDC – OAS and CPP Statistics book (Report available by request from HRSDC)	Net benefits paid by fiscal year
EI Sickness	EI Monitoring and Assessment Report, Annex 2 http://www.servicecanada.gc.ca/eng/sc/ei/benefits/sickness.shtml	Amount paid by fiscal year

(continued)

Income support category	Data source(s)	Methodology
Veterans' Disability Pension & Awards	Office on Disability Issues annual report, appendices for national data http://www.veterans.gc.ca/eng/services/disability--benefits/disability--pension HRSDC's Social Security Statistics report, Table 154 for provincial estimates (Available by request from HRSDC)	Provincial data estimated based on provincial distribution of Disability Pensions reported in unpublished Social Security Statistics report
P/T Social Assistance Programs	Provincial and territorial public accounts, main estimates and annual report	Only five provinces – New Brunswick, Ontario, Manitoba, Alberta and B.C. – report disability fiscal year expenditures for Social Assistance A national figure of 55% of total SA expenditures is used to estimate SA expenditures on people with disabilities based on these data
First Nations Social Assistance	HRSDC's Social Security Statistics report, Table 141 (Available by request from HRSDC)	First Nations spending on people with disabilities has been estimated based on the national estimate of 55% of total spending.
Workers' Compensation – provincial/territorial	Association of Workers Compensation Boards of Canada – Key Statistical Indicators – Basic Accounting Measures, line 51 minus line 5.11 https://aoc.awcbc.org/KsmReporting/ReportDataConfig	Amounts represent net benefits paid less benefits for health and rehabilitation services
Workers' Compensation – federal	Office on Disability Issues annual report appendices http://www.labour.gc.ca/eng/health_safety/compensation/	
Private Disability Insurance – STD and LTD	Canadian Life and Health Insurance Association (Available by request)	Based on Direct Claims paid, which represent the actual amounts paid to insured individuals

ONTARIO DATA SOURCES, 2010–11
2010–11 Public Accounts, Vol. I. See page 2-93, financial assistance amounts only. OW amounts have been increased to reflect the municipal contribution.
http://www.fin.gov.on.ca/en/budget/paccts/2011/11vol1eng.pdf

Disability and Employment Research: Mind the Gap

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Douglas Waxman

Contents

Abstract

This chapter examines the gap in how we study disability employment by examining 130 studies from 2000 to 2022 on employers' perceptions of employees with disabilities. Most of the studies are subject to social desirability bias, being largely based on employer self-reports. Expressed intention has been shown not to be coincident with employers' actual behavior. Another gap identified include a lack of generalizability of research studying employers' perceptions of employees with disabilities. A further gap is that this concept is understudied in the Global South. Researchers are challenged to find data that gets at employers' actual behaviors. A potential example of such research is provided. The annexed annotated bibliography of extant literature on employer's perceptions and behaviors towards employees with disabilities is a significant resource.

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Gap in the Extant Literature

Employment is considered essential, in addition to remuneration, for its contribution to human flourishing, self-actualization, and dignity. The right to equality in employment for persons with disabilities is enshrined in multitudes of national human rights codes and at the international level in the *Convention on the Rights of Persons with Disabilities*. And yet, persons with disabilities continue to be underutilized, subject to involuntary unemployment despite having untapped work capacity. This persists even in tight job markets. Persons with disabilities are subject to high rates of employment discrimination. This apprehension to hiring persons with disabilities clearly derives from employer biases.

Barriers to disability employment is an important construct to study if we hope to overcome the gap between the work potential of persons with disabilities and their actual utilization. Not only what we study is important but so is how we study disability employment if we hope to fully understand the issues. While there seems to be considerable research on employers' self-reported perceptions of employees with disabilities, little research has been conducted that surfaces employers' actual behaviors towards employees with disabilities. We have a multiplicity of focus groups and survey data, where employers speak favorably about the potential of employees with disabilities, but given the low levels of employment of persons with disabilities, they seemingly do not actually hire persons from this population.

Not only is there a gap in the utilization of persons with disabilities in the labor force but there is a gap in how we study this issue. In order to further understand the research gap, an exhaustive survey of the extant literature is presented here. While the substantive findings of the various papers referenced are significant in their respective research contexts, their import here is for what they tell us cumulatively about the state of research methodology in the field of disability employment discrimination. It will become apparent from the extensive review of the extant literature and examination of methodologies applied that there is an overreliance on employer s' self-reporting, which is often disconnected from employers' actual behaviors. It is argued here that there is a gap in methodology in how we study employers *vis á vis* employees with disabilities, in that we principally focus on what employers say not what they actually do.

Methodology

This research was conducted initially as part of the literature review for my doctoral dissertation (Waxman, 2022). The study involved initial systematic database searches primarily using Google Scholar. Searches used combinations of key search terms: employees with disabilities, employer, behaviors, perceptions, preferences, attitudes, beliefs, and perspectives.

The time frame for the searchers was bound by the years 2000 to the present. The year 2000 presented a natural (if somewhat arbitrary) breakpoint, giving a date range sufficiently far back so as to capture the significant works on this construct and methodological trends but without reaching back so far as to include pieces that may be outdated. There would only be a few studies prior to 2000. Twenty-two years provides a significant time frame to assess the state of research and view trends.

The research was primarily iterative. Reading various pieces of the literature leads to other referred literature meeting the search criteria. I refer to this form of literature retrieval as akin to the snowball sampling technique. This search technique allows access to articles about preferences, attitudes, and behaviors not caught by searches using key terms. Ultimately, the initial round of research bound by the years 2000–2017 led to 95 papers.

In subsequent years, I collected further literature on the concept of employers' perceptions of employees with disabilities as they became available. This aggregation was largely passive, collecting relevant articles as they appeared on feeds from Academia, Research Gate, Mendeley, and Science Direct. My continued reading to research employers' discrimination towards persons with disabilities led to unearthing other papers. In total, this generated 35 additional papers on the concept of interest. Thirteen of those papers related to the original search period 2003–2017. The balance was research published in 2018–2022. Thus, the total literature sample was 130 papers.

Papers that did not expressly discuss employer or managers' behaviors or attitudes were excluded. Papers about more general perceptions of disability that did not have an employment component were excluded. Papers about best practices for employing persons with disabilities were excluded, unless they had some element of employers' perception or behaviors. Papers that examined employer attitudes towards certain labor activation policies were also excluded. Articles focused on hiring or accommodation best practices but not assessing behaviors or attitudes towards employees with disabilities were excluded. Papers that addressed the concept but were only about validating a survey scale measuring employers' dispositions without providing findings about employers' attitudes or behaviors were excluded. Papers surveying discrimination generally, including disability, were excluded. Papers about employees' or coworkers' attitudes towards persons with disabilities were also excluded. However, the excluded papers contributed to the snowball effect as a source of other papers dealing with employer disability-related preferences. Consideration was given to excluding studies where the subjects were university students; however, this is a relatively common source of research data and only represents four studies (Gouvier et al., 2003; Louvet, 2007; Requero et al., 2020; Weigand, 2008).

The vast majority of the studies are published in academic journal articles. Seven are reports emanating from governments, research institutes, and consulting firms. However, most of the reports use academic methodologies. They consist of two surveys, three literature reviews, one focus group, and one mixed method, including interviews and online submissions. Searches were not conducted on a country-by-country basis, which may have generated reports from other countries that were not otherwise caught. Regardless, it is likely that adding such studies would only skew the survey, focus group, interview, and literature reviews categories further. It is unlikely that government studies, which are the most prevalent of the three non-journal sources (n-3), would conduct experimental research.

Profile of the Research Studies

As can be seen from Fig. 1, 2011–2015 seems to be the zenith of research productivity in this field. Fifty-four of the 130 studies, or 43%, occurred over these 5 years. In comparison, in the preceding 10 years, only saw 43 studies conducted on the issue. This 10-year period's lower number may reflect the nascent state of disability employment research. Searches only netted 30 studies for the 6 years, from 2016 to 2021. It is unclear whether this reflects a sense of saturation or an appreciation of methodological limitations. The lower number (n-4) for 2020 and 2021 may be due to the COVID pandemic. However, 2016 (n-2) and 2019 (n-4) also had similarly low volumes of research in this area. The current year (2022) is excluded from this discussion, given that it represents, to date, an incomplete year and, therefore, is not comparable.

The national origins of the studies, as seen in Fig. 2, are dominated, as expected by the Global North. One hundred sixteen (116) of the studies, or 88%, are from the Global North (including Australia, Israel, South Korea, and Taiwan). Of those, 77 were from America and Canada. Fifty-two of those were from America. The field is clearly dominated by research from America and is North American-centric. This ratio in studies might be altered if the search included literature in other languages. This might be considered a limitation of this study.

There were only 16 studies from the Global South. Regionally, there were 2 studies from Africa (South Africa and Zimbabwe), 11 studies from Asia, 1 from the Middle East (Saudi Arabia), and 2 from South America. The Asian numbers were dominated by India and Malaysia, with four studies each. The South American

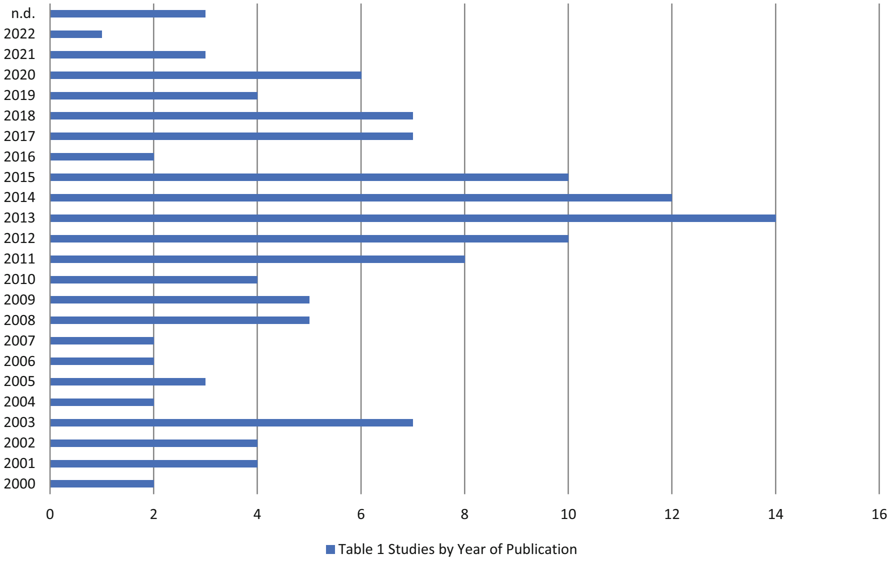

Fig. 1 Studies by year of publication

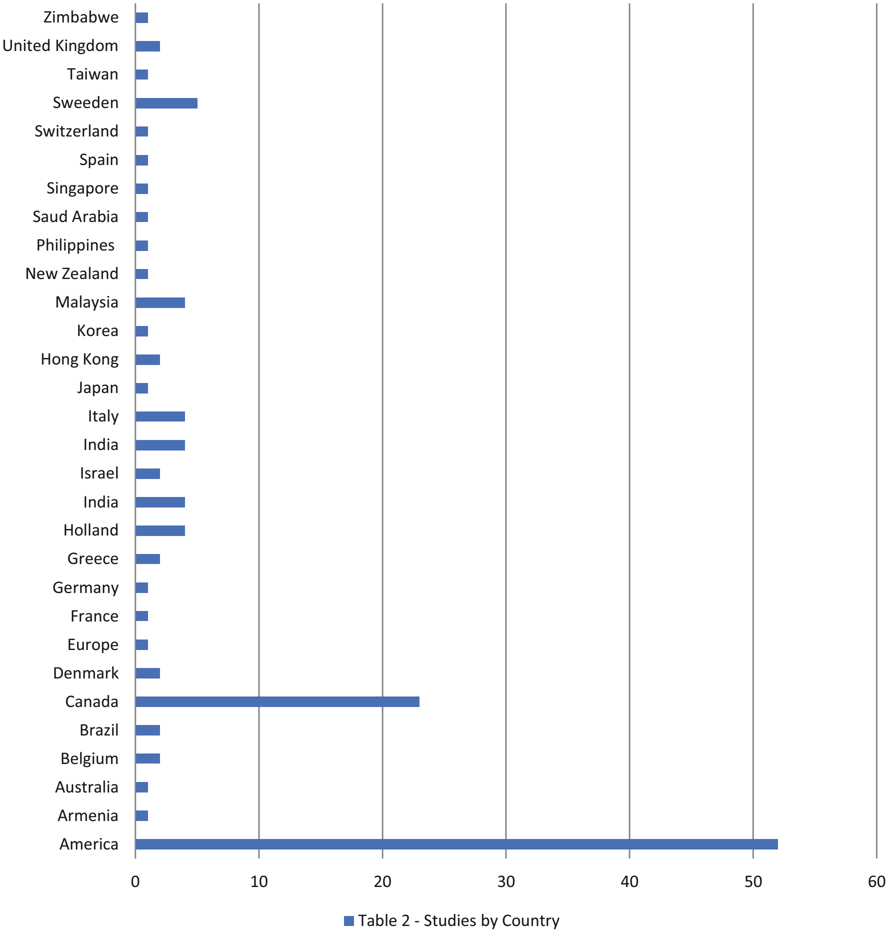

Fig. 2 Studies by country

studies were both from Brazil. There were no studies from Latin America. Studies from the Global South ranged from 2003 until 2022. However, 13 of the 16 studies were from 2014 to 2022. The low number of studies from the Global South is not surprising. As Meekosha (2008) notes, "Little is documented about disability in the non-industrial world" (p. 2). Hwa (2017) states, for example, "Disability research in the Asia context is also still few and far between, resulting in a dearth of data on the disabled population (p. 2). And Katsui and Swartz (2021) note that increases in disability studies in the Global South are recent. Employers' behaviors towards persons with disabilities in the Global South remain understudied and thus there is a geographic research gap as well.

As with the North, in the Global South, surveys dominate the methodology landscape, consisting of 8 out of 16 studies, followed by 4 interviews, 2 literature reviews, 1 mixed methods study, and 1 experimental study. Thus, the methodological gap, as will be discussed in the next section, persists both in the Global North and South, except in the Global South, as mentioned above, it remains understudied.

Intention Versus Behaviors

Most of the extant research measures managers' intentions, as can be seen by the level of research reliant on employer self-reports. Few assessments of employers' actual behaviors have been conducted. Typically, research has attempted to gauge employer attitudes toward employees with disabilities to judge employers' prejudices as barriers to employment. Hernandez et al. (2008) pointed out that there are many studies examining employers' perceptions of workers with disabilities, of which the vast majority are quasi-experimental designs or quantitative surveys. They note, "While such data are valuable, the in-depth experiences of employers have not been more fully explored" (Hernandez et al., 2008, p. 158). The review of the literature from 2000 to 2022 concerning employers' perceptions of employees with disabilities (Appendix) reveals 130 studies of this construct. As can be seen from Fig. 3, the majority, 61 studies, are surveys, followed by 20 interviews, 6 mixed methods, 8 focus groups, 19 experimental designs, 20 literature reviews, 1 theoretical review, and 1 essay that does not disclose methodology.[1] Taken together, 95 of the research papers were dependent on researcher self-reports, thus evidencing a gap in how we study disability employment, that does not actually surface employers' actual behavior towards employees with disabilities.

Studies from Israel, the United States, the Netherlands, and Sweden reveal that managers' intentions are not a significant predictor of actual behavior (Andersson, 2012; Araten-Bergman, 2016; Hernandez et al., 2000; Sālājeanu, 2012; Zissi et al.,

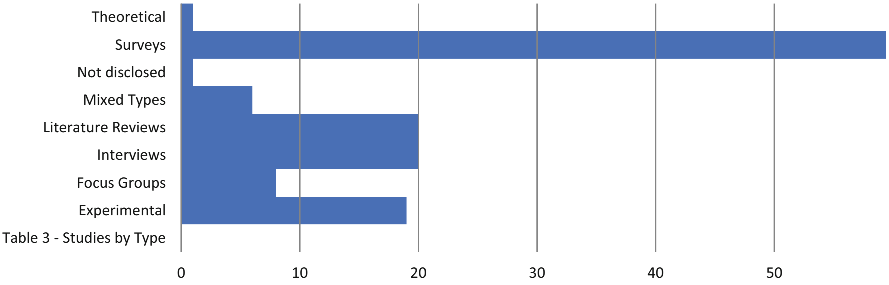

Fig. 3 Studies by type

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[1] Peck and Kirkbridge (2001) does not advert to a method but is a fairly foundational, early discussion of employers' attitudes, so it has been retained.

2007). As Araten-Bergman (2016) stated, most studies use “managers’ expressed intentions as an adequate proxy for actual hiring, making little effort to validate the conjecture” (p. 1511). Araten-Bergman (2016) further stated that, “although potential employers generally tend to express positive attitudes and a willingness to hire PWD in employers’ surveys, they rarely do so in real-world situations” (p. 1511). Bredgaard and Salado-Rasmussen (2021) distinguish between attitudes and behaviors. “Employers generally express positive attitudes towards recruitment of persons with disabilities. Field experiments of actual recruitment practices, however, reveal that employers are less likely to invite job applicants disclosing disabilities compared to job applicants without disabilities” (p. 4). That is, employers’ positive attitudes about employees with disabilities do not translate into corresponding hiring behaviors.

Research Quality

Most of the nonexperimental studies do not get at actual lived experience and discrimination. At best, according to Ren et al. (2008), correlation studies frame research questions that need further exploration through experimental investigation. However, not all experimental designs get at actual behavior. Kulkarni and Lengnick-Hall (2014) note a disconnect between laboratory and field studies, pointing out that the former are more likely to demonstrate positive attitudes towards employees with disabilities. Further, the analogue nature of certain experimental designs means that the results are not generalizable (Cook & Rumrill, 2005).

Most surveys in the literature that are created to reveal employers’ attitudes toward persons with disabilities are designed by individual research teams. Lengnick-Hall et al. (2001) pointed out that only a small percentage of the structured surveys reviewed used validated scales. Lindsay et al. (2013) note that most disability employment research “lacks a rigorous design” (p. 9). The review of the studies in Appendix found that a few used published scales. However, at least 24 of the studies relied on researcher-constructed surveys. Most of these studies, if not all, are limited by the absence of preexisting psychometric development (Antonak & Livneh, 2000; Mak et al., 2014; Palad et al., 2016). In an extensive review of the organizational behavior literature, Hinkin (2008) found that “inappropriate domain sampling, poor factor structure, low internal consistency and reliability and poor reporting of newly developed measures continue to threaten our understanding of organizational phenomena” (Hinkin, 2008, p. 1). As Lengnick-Hall et al. (2001) noted, “While author-created surveys are not necessarily, by definition, lacking validity, their one-time use makes them difficult to assess” (para. 4). It has been found that there are conflicting findings with respect to various factors on acceptance of employees with a disability (Unger, 2002; Vornholt et al., 2013), which suggests concerns about the reliability and generalizability of the studies. Another significant gap is the lack of longitudinal studies (Heera & Devi, 2016; Vornholt et al., 2013), with the exception of the study by Araten-Bergman (2016). The lack of generalizability is often a necessary and accepted limitation in qualitative research and while all the studies in Schedule A contribute to our understanding of the disability-employment construct, there may be an overall lack of generalizability in how we study employers' perceptions of employees with disabilities, which contributes a methodological gap.

Social Desirability Bias

The most significant issue with self-reported data is its potential to be confounded by social desirability bias, which may skew the data. This bias is the result of respondents deliberately distorting their views, chiefly to give a good account of themselves or to provide a socially appropriate response (Antonak & Livneh, 2000; Araten-Bergman, 2016; Wilson & Scior, 2015), which the researcher then, "interprets as a meaningful, typical or stable attitude" (Antonak & Livneh, 2000, p. 215). Bredgaard and Salado-Rasmussen (2021) note that survey research is more susceptible to social desirability bias than field experiments. Some papers in Appendix indicate that social desirability bias is a possible limitation of the survey research (Araten-Bergman, 2016; Gustafsson et al., 2014; Jasper & Waldhart, 2013; Wilson & Scior, 2015). Further, Wilson and Scior (2015) found no association between implicit attitudes, which were somewhat negative, and explicit self-reported attitudes towards, in that research, persons with intellectual disabilities.

Robert and Harlan (2006) advise "that motivations are unobservable and empirically unverifiable … they must be imputed based on indirect evidence" (pp. 601–602). "That motivations are unobservable and empirically unverifiable" leaves us with indirect evidence. The indirect evidence would be employers' actual behaviors. And while all the forms of research enumerated above add to the cannon of disability studies and contribute to our understanding, for which we owe a debt of gratitude, we, in the disability-employment academy, need to focus more on surfacing actual employer behaviors than empirically unobservable intentions and attitudes.

No doubt, finding sources of data evidencing actual employer discriminatory behavior to study is challenging, particularly in the world of work characterized by aversive discrimination (Deal, 2007; Friedman & Owen, 2017; VanPuymbrouck et al., 2020). That is, norms in modern society make it less acceptable to discriminate on an overt basis, such as disability. Most employers are sophisticated enough not to be honest in rejecting a job applicant overtly because of their disability, for example.

The Challenge

Finding data that renders employers' behaviors that are not dependent on employers' intentions or confounded by employers' attempts to be socially acceptable is a challenge and necessitates researchers to be creative. Waxman (2022) recent research is humbly offered as a potential example of using such data for researching employers' behavior. In an effort to contribute to filling the gap in the literature, Ontario Human Rights Tribunal cases were utilized. The cases were culled down to those in which the employer was found in breach of the *Ontario Human Rights Code* on the ground of disability discrimination in employment. These cases were an untapped resource, as they have never been used empirically for this purpose. They are an abundant source of relevant data, as Tribunals Ontario (2020) reports that 62% of Ontario Human Rights Tribunal cases were on the grounds of employment, and 53% of the claims were on the grounds of disability.

Legal cases have the benefit of being a source of naturally occurring data (Darcy et al., 2016). As Silverman (2006) stated, "Naturally occurring texts document what participants are actually doing in the world – without being dependent on being asked by researchers" (p. 163). The cases as a data set constitute a random sample. Given the way the Human Rights system works, there is no way to predict or control which cases would meet the established search criteria. There is no way to know what claimants will bring a claim, and out of the thousands of cases filed annually, which ones will not settle out or be subject to dismissal for various procedural reasons. Moreover, the cases, as data, are less susceptible to social desirability bias, given that the behavior has already occurred (Potter, 2004; Silverman, 2006). They are retrospective data from which employers' actual behaviors could be studied. Unlike susceptible data, cases could be relied on as presenting "meaningful, typical or stable" information (Antonak & Livneh, 2000, p. 215). Documents have been recognized as being able to consist of an entire study (Charmaz, 2014; Glaser & Straus, 1967; Pandit, 1996; Turner, 1983). Legal decisions are a valid source for empirical document analysis (Darcy et al., 2011, 2016; Darcy & Taylor, 2009; Hall & Wright, 2008). Hall and Wright (2008) note legal cases are no more imperfect than other forms of social science data; "though judge-reported facts may not 'purport to be the real facts' they are 'near enough'" (p. 97).

It was found that employers were saying one thing, proffering a bevy of excuses, but the adjudicators, upon looking at the evidence, i.e., the employers and employee behaviors, were able to determine a different, more accurate picture of employment in each of the cases examined. However, the adjudicators found none the reasons (defenses) offered by the employers to be true, on the balance of probabilities. What employers stated was disconnected from the actual evidence. The employers' actual behaviors differed from the employers' assertions. The most significant conclusion is that the employers' discriminatory behavior differed from their espoused reasons.

Limitations

That this research was not systematic in adhering strictly to database searches bound by key search terms, in the classic sense, may be a limitation, which is admittedly ironic in a review of methodology. I would, however, argue it is comprehensive and relatively exhaustive of the literature on the concept. Systematic research also misses relevant literature and is as good as its search terms. The research is sufficiently robust to opine on the state of how research of the concept in question is being conducted. Another possible limitation is that searches did not include specific disabilities or specific countries, or studies in languages other than English (with the exception of Zappella, 2015a), which may have led to additional studies.

Conclusions

The review of the studies of employers' perceptions of persons with disabilities from 2000 to 2022, presented here, contributes to understanding how researchers have studied this phenomenon and identifies a gap in our knowledge resulting from the type of methods deployed. The extensive literature canvased here revels that researchers largely rely on self-reported intentions of employers, which are subject to social desirability bias. The disconnect between what employers say and what they do evidences a gap in the methodology researchers utilize to study the phenomena of employers' behavior towards persons with disabilities. Further, we see other gaps in the generalizability of the typical research methods used to study this construct, as well a global gap in the disability employment being understudied in the Global South.

The challenge for researchers seeking to understand employers' discrimination of employees with disabilities is to find creative ways to get at employers' actual behaviors. All research contributes to our understanding of this phenomenon. However, there is a need to move beyond employers' self-reported attitudes or intentions.

Given that unemployment of persons with disabilities wastes human capital is a barrier to individual self-actualization and increases demand on social welfare systems, it is essential that we deepen our understanding of the barriers impeding employment of persons with disabilities in all its complexity. Therefore, researchers must continue to find data that accesses employers' actual behaviors and fills the gap.

Appendix

Studies on employers' attitudes towards persons with disabilities 2000–2021

Study	Year	Location	Methodology	Sample Size	Focus	Findings
Alfasi	n.d.	Israel	Survey	1900 businesses		Generally, no difference in attitude between firms employing persons with disabilities and those not employing persons with disabilities was found
Ameri, Schur, Adya, Bentley, et al.	2015	The United States	Field experiment (sent three different applications)	6016 advertised positions		Applications with disabilities received 26% fewer expressions of interest
Andersson	2012	Sweden	Survey	68 head hunters or employers	Psychological disabilities	Employers hold favorable attitudes towards persons with disabilities
Andersson, Luthra, Hurtig, and Tideman	2015	Sweden	Survey Vignette	212 employers		Employers' interest in hiring persons with disabilities varies with the nature of the disability and their previous experience with persons with disabilities. Employers with experience with persons with disabilities were more interested in hiring persons with disabilities and believed they were more open to hiring employees with disabilities than other employers. Access to financial compensation, extra resources, guidance, and openness about disability was seen as essential
Ang	2017	Japan and Malaysia	Semi-structured interviews	20 hiring managers		Found a belief that persons with disabilities are incapable of work. Malaysian respondents stated a lack of suitable work and that hiring was motivated by the company's corporate social responsibility agenda

(continued)

Study	Year	Location	Methodology	Sample Size	Focus	Findings
Annett	2017	Canada	Semi-structured interviews	6 supervisors		Supervisors perceived risks of hiring persons with disabilities in cognitive terms, largely associated with increased workload for themselves
Applications Management Consulting Ltd.	2014	Canada	Survey – annual Calgary and area labor market report	801 business	Dispel myths and provide more information	53% of employers surveyed do not employ persons with disabilities Only 15% proactively recruited persons with disabilities 49% were unaware of available employment supports More can be done to understand employers' concerns
Baker, Linden, LaForce, Routledge, Goughnour	2018	America	Comparative literature review	200 articles		The themes that emerged include variance in employer perspectives on hiring individuals with disabilities, the impact of perceived versus actual cost as a hiring barrier, and the perceived mismatch of education and/or skills to job qualifications among applicants with disabilities There is a knowledge translation gap between both academic and business literature
Araten-Bergman	2016	Israel	Survey Theory of Planned Behavior Questionnaire Longitudinal (6 months)	146		The Theory of Planned Behavior failed to predict actual hiring Managers' intentions were not significant predictors of actual behavior

Baert	2016	Belgium	Field experiment	768 job vacancies		The likelihood of a disabled candidate receiving a positive response to a job application is not positively influenced by disclosing entitlement to a wage subsidy
Baert, De Visschere, Schoors, and Omey	2014	Belgium	Experimental Matched pair	304 job vacancies	Depression	Identifying previous depression as a reason for unemployment is rewarded by female recruiters and is treated negatively by males. Depression is also treated less favorably in low-skill occupations
Mapuranga and Mutswanga	2014	Zimbabwe	Interviews	10 employers 10 coworkers 10 employees with disabilities		Employers felt that some persons with disabilities were not as competent, would scare away customers, and some were dependent on coworkers to complete tasks, were ignorant, and had poor time management. While managers tend to reject disability as divine will, there is a prevalence of charitable attitudes. Most see disability as a social problem, while some see it as an individual problem. Many managers see hiring persons with disabilities as affected by organizational contextual factors aside from performance. These conceptions influence integration vs segregation attitudes
Beaton, Kabano, and Léger	2012	Canada	Associative techniques, open-ended and semi-structured interviews	64 directors of human resources or head of the company		They found implicit discrimination or aversive disablism Employers apply the logic of the labor market as a way to evaluate persons with disabilities Employers associate that different is incompatible with their business priorities in

(continued)

Study	Year	Location	Methodology	Sample Size	Focus	Findings
						that they perceive limitations, underperformance, increased cost, and extra supervision
Bell and Klein	2001	The United States	16 experimental conditions Ranking of hypothetical job applicants	98 psychology undergraduates 88 employees		An applicant with paraplegia was ranked higher for activity and potency than an applicant with depression or an applicant without a disability All three applicants with a disability were ranked higher on activity than the applicant without a disability, and the applicants with paraplegia and epilepsy were rated higher for potency than the applicant without a disability Female applicants were ranked higher than male applicants on all variables except potency Male applicants were ranked higher than female applicants for supervisory roles, but females were ranked higher for non-supervisory roles
Bellemare, Goussé, Lacroix, Marchand	2018	Canada	Field experiment	1477 private firms	Mobility impairment	Found mention of disability in job application reduced incidences of call back by 50%. Signaling a subsidy to adapt the workplace does significantly reduce discrimination
Bendick	2018	The United States	Experimental Matched pair	31	Mobility	Those with a disability were only 27% as likely to receive a job offer or otherwise advance as far in the hiring process compared to their equally qualified counterparts without a disability. Discrimination, either conscious or

						unconscious, was documented by 41% of retailers tested
Benoit, Jansson, Jansenberger, and Phillips	2013	Canada	Mixed methods Quantitative analysis of Participation and Activity Limitation Survey 2006 Semi-structured interviews	41,750 18	Blind	They found very low labor force inclusion and lower inclusion than other disabilities They found the major barrier is stigma
Bonaccio, Connelly, Gellantly, Jetha, Ginis	2019		Literature review	Literature addressing 11 specific concerns that employers have about people with disabilities		Based on empirical evidence, examines employers' concerns about employing persons with disabilities across the various components of the employment cycle
Boni-Saenz, Heinemann, Crown, and Emanuel	2006	The United States	In-depth semi-structured interviews Four case studies Longitudinal	Interviewed CEOs and other senior management executives, directors of human resources, hiring managers, recruiting specialists, and directors of		Businesses generally employ people with disabilities because of some commitment that derives from a variety of sources The major perceived benefits of hiring people with disabilities focused on the diverse perspective they provide to the company and the loyalty they show the company that hires them The major perceived barriers to hiring people with disabilities included attitudinal barriers Smaller companies see employing people with disabilities as a larger risk than larger

(continued)

Study	Year	Location	Methodology	Sample Size	Focus	Findings
				diversity and inclusion, in each of the four businesses		companies perceive. Larger companies also had differing views of the *Americans with Disabilities Act*, with larger companies having a more positive view of the law Companies generally desired vocational rehabilitation and job counsellors to aim for a good match between an applicant with a disability and the job position rather than just a placement. Lack of business knowledge among vocational rehabilitation counsellors was a complaint Health care costs were not seen as a barrier Companies do not generally use tax credits to employ people with disabilities or for accommodations Outsourcing is a serious issue in the technology sector for people with mobility impairments. As with "offshoring," outsourcing eliminates a large class of entry-level jobs and telecommuting opportunities for individuals with disabilities. In addition, the opportunities that are still available in the United States may not present the same opportunities for career advancement as they would if the jobs were still housed in a large, disability-friendly corporation
Bredgaard, Salado-Rasmussen	2021	Holland	Survey of employers' attitudes,	1901 hiring managers		They found a moderate but significant correlation between employer attitudes and behaviors

			experiences, and behaviors			
Breen, Havaei, Piassi	2019	Armenia	Questionnaire – Perceived Barriers to Employing Persons with Disabilities Scale	158 employers		Found that employers were more concerned about acceptance by supervisors, coworkers, and customers than about performance (though this was also a factor). This result differs from findings in other jurisdictions
Bricourt and Bentley	2000	The United States	Survey Employers' employability ratings of hypothetical job applicants *Employment Characteristics Scale*	248 hiring managers		Nondisabled job applicants were rated more employable than applicants with severe disabilities Employees with acquired brain injury and schizophrenia were rated similarly
Brite, Nunes, Souza	2015	Brazil	Survey – Conceptions of Disability Inventory	90 managers	Supermarkets	Managers' perceptions regarding people with disabilities contribute to their actions of inclusion or exclusion
Borghouts-van de Pas, Freese	2021	Holland	Mixed methods – interviews and focus groups	38 employers		Employers respond to institutional pressures (quotas) in a contextual and strategic way assessing environmental, strategic, organizational, and internal fit
Burke, Bezyak, Fraser, Pete, et al.	2013	The United States	Literature Review	34		The study found that employers were either very optimistic or very pessimistic about employees with disabilities' skills. Employers need accurate information to dispel myths

(continued)

Study	Year	Location	Methodology	Sample Size	Focus	Findings
Center for Information, Training & Evaluation Services, Florida State University	2003	The United States	Survey	306 businesses		Persons with prior experience with employees with disabilities have a more favorable attitude, as do employers with formal disability policies Behavioral disabilities were perceived as the hardest to accommodate Employers may not be aware of available workplace supports and programs Two out of three employers were unaware of disability issues
Chan, Strauser, Maher, Lee, Jones, and Johnson	2010	The United States	Survey *SPR/nAblement Employer Survey*	132 human resource managers and line managers		Managers are moderately positive (ambivalent) about the productivity and reliability of employees with disabilities Barriers identified are (1) lack of commitment to including disability in companies' diversity plans, (2) lack of resources to recruit and retain persons with disabilities, and (3) inadequate training in ADA and workplace accommodations Points 1 and 2 are key predictors of corporate and management commitment to hiring persons with disabilities
Chan Ho-ting and Wong Ming-Wai	2015	Hong Kong	Mixed methods – interviews Survey	8 209		This research discusses perceived additional costs of training, supervision of accommodation, lack of management commitment, and concern over requisite skills

Chen, Blankenship, Austin, Cantu, and Kotbungkair	2016	The United States	38-item Employer Attitudes Questionnaire and 33-item Small Business Owners Survey	270 Hispanic small business owners	Hispanic small business owners	This research discussed significant predictors of hiring persons with disabilities: prior contact with persons with disabilities, marital status, and awareness of the ADA
Chi-Geng	2004	The United States	Survey	500 restaurant employers	Restaurant sector	This research found that employers preferred persons with sensory impairments or physical disabilities to those with mental disabilities Employers' attitudes towards employees with sensory impairments and physical disabilities had a positive impact on the probability of employing persons with disabilities Prior work experience with disabled persons leads to a more favorable attitude towards employees with disabilities
Copeland, Chan, Bezyak, and Fraser	2010	The United States	Survey *Disability Questionnaire*	142 employers		The findings support the reliability of the scale Employers did not have significant negative cognitive or affective reactions towards employees with disabilities. Employers had a moderately positive attitude towards accommodations Employers had a high positive attitude towards treating these employees like other employees Experience working with persons with disabilities can result in a high positive attitude

(continued)

Study	Year	Location	Methodology	Sample Size	Focus	Findings
Deloitte	2010	Canada	Focus group Roundtable	90 representatives from business and government agencies, employees		This identified barriers to employment, accommodation, and accessibility, including attitudes and myths, the business case, and the need to educate individuals involved in hiring and solutions
Deuchert, Kauer	2013	Switzerland	Field experiment	384 applications		Found that the subsidy is ineffective or even counterproductive in a group of adolescents who are at the end of their vocational training program but may increase callback rates of clients of job coaching services. For the first group, the subsidy signaling effect is stronger, while for the second group, the incentive effect is stronger
Deuchert, Kauer, and Zannol	2011	Switzerland	Discrete choice experiment	533	Mental disorders	They found few employers willing to train apprentices with special needs, even though there were no direct costs. Very low acceptance rate of the employee profiles presented. Noncognitive dysfunctions are the main deterrent
Domzal, Houtenville, and Sharma	2008	The United States	Survey	3797 companies		Large companies are more likely to hire Small and medium-sized companies require information about job performance and are more concerned about health care costs and workers' compensation premiums, and they prefer employer tax credits Large companies found their challenge to be in recruiting and prefer mentoring as a strategy The nature of the work was more of a

						concern in industries with physically demanding work For companies that employ persons with disabilities, there is more of a challenge around advancement than the attitudes of customers or coworkers The public sector is more likely to recruit persons with disabilities than the private sector
Drydakis	2009	Greece	Field experiment	862 applications	HIV	Uninfected applicants were systematically preferred over applicants that disclosed their HIV-positive status. The results imply that employers use health conditions as a screening factor
Ebrahim, Lorenzo, Kathard	2022	South Africa	Case study – critical conversation interviews	Two employers		Employment of persons with disabilities is motivated by obligations to fulfill mandates. They are seen not for their ability but by their impairment
Employment Monitoring and Evaluation Branch	2011	Australia	Survey Online Employer Forum	1230 40		Key findings from 2011 online employer forum: (1) Honesty up front should be encouraged. (2) Employment is all about getting the right person for the job. (3) Workers with a disability are often considered the more reliable and loyal employees. (4) DES support plays a large role in the employment decision. (5) Financial incentive is a decision helper and not a deal breaker (for most). (6) Employer incentives are deemed to be more than just wage subsidies (for most). (7) Ideally, for employers, financial

(continued)

Study	Year	Location	Methodology	Sample Size	Focus	Findings
						incentives are linked to worker productivity and are paid in instalments. (8) Employers desire incentives to be longer and more substantial. DES providers are highly praised The standout message from the forum is the importance of getting the right person for the job
Fraser, Ajzen, Johnson, Hebert, and Chan	2011	The United States	Survey Theory of Planned Behavior	92		This research looks at how companies' size affects norms and control beliefs and how small, medium, and large companies' concerns regarding hiring persons with disabilities vary
Fraser, Johnson, Hebert, Ajzen et al.	2010	The United States	Semi-structured focus groups Theory of Planned Behavior	20		This research found that education and marketing approaches to companies hiring persons with disabilities need to be tailored based on company size Behavioral concerns include fear of potential litigation, loss of revenue, and fear of affording changes for physical accommodation Normative concerns, including coworker and management attitudes Control beliefs around effectiveness and efficiency of contact with vocational rehabilitation Behavioral concerns were more salient to small companies, with normative concerns being more relevant to midsize companies. All companies, independent of size, were concerned with the control issue

Fredeen, Martin, Birch, and Wafer	2013	Canada	Mixed methods About 70 in-person and telephone interviews Consultations Approx. 130 online submissions	About 200 employers		Education and training are required to overcome barriers, dispel myths, and put theory into practice
Gaspeer, Muz, Palan	2020	America	Survey of Employer Policies on the Employment of People with Disabilities	2023 senior executives		Found increases in the percentage of companies that employ, recruit, and hire persons with disabilities compared to the 2008 survey The most frequent concern was about safety on the job Concerns were higher among small firms and in the goods-producing sector Concerns were higher among owners and chief executive officers vs. human resources, supervisors, and managers
Gaspar	n.d.	India	Questionnaire	40 human resource managers 40 disabled employees		Found employees with disabilities were considered to have appropriate social behaviors and satisfactory loyalty to the organization and performance. Respondents agreed with the provision of accommodations but believed it is difficult to terminate an employee with a disability. Managers are concerned about health and safety expenses, and that extra supervision will be required. They believe hiring persons with disabilities will improve corporate image

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Study	Year	Location	Methodology	Sample Size	Focus	Findings
Gatchalian et al. (Abstract only)	2014	Philippines	Survey of employers and HR practitioners	210		Employers generally have positive attitudes about persons with disabilities. Attitudes vary with the company and disability characteristics
Gilbride, Stensurd, Vandergoot, and Golden	2003	The United States	Focus groups and interviews Grounded theory	16 successfully employed consumers 39+ employers 8 placement service providers		This research discusses three major categories of characteristics (comprising 13 specific characteristics of employers open to hiring and accommodating persons with disabilities): inclusive work, cultural issues, quality job match, employer experience with diversity and support in accommodating
Gould-Werth, Morrison, Ben-Shalom	2018	The United States	Semi-structured interviews	14 human resource professionals rendering 50 cases		Found that employers' efforts to accommodate and retain employees were affected by the employees' previous work performance, physically active work vs. sedentary work: the type of health condition, the employee's available resources, and the ability to communicate across stakeholders. Employers are less likely to make an effort to accommodate poor performers or employees of short duration
Gouvier, Sytsma-Jordan, and Mayville	2003	The United States	Experimental – four medical conditions and four sample resumes for two job positions Forced choice	295 undergraduate, business-related major students		The authors found hiring discrimination varies as a function of the type of disability and the interaction of the type of disability with contextual variables Physical disabilities are more likely to be preferred over mental disabilities

Graffam, Shinkfield, Smith, and Polzin	2002	Australia	Survey	643 employers who had employed persons with disabilities		Employers place the greatest emphasis on work performance both individually and as it affects the organization/work group Four underlying employer values were identified: (1) they value their business, so factors affecting the business were of greater importance, (2) factors related to personal performance were ranked highly, (3) they value the whole organization, so they consider social integration/acceptance as a factor of job performance, and (4) they value partnership and expect employment services and employees to consult in planning, implementation, and maintenance of the job
Gröschl	2007	Canada	Qualitative semi-structured interviews	42 hotel managers	Hospitality industry	This research identified a number of barriers to hiring persons with disabilities in the hospitality industry due to managers' perceptions, such as lack of legislative pressure, concerns around aesthetics, productivity, training costs, accommodation costs, inflexibility, and the need for constant management
Gröschl	2011	Germany	Case study Semi-structured interviews	5 integrated hotels		This research concludes that artificial barriers (perceptions and stereotypes) of employers at nonintegrated hotels are barriers to greater disability inclusion
Gustafsson, Peralta, and Danermark	2014	Sweden	Semi-structured interviews Content analysis	19	Wage subsidies	Four factors were found: employers' attitude (based on previous experience with persons with disabilities), job matching, wage subsidies as incentives, and the necessity of soft accommodations. The cost was less important than performance

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Study	Year	Location	Methodology	Sample Size	Focus	Findings
Hand and Tryssenaar	2006	Canada	Cross-sectional survey involving interviews and a questionnaire	58 employers	Mental health	Employers have concerns about persons with disabilities characteristics and particularly their work personalities, and concern over potential violence
Hartnett, Stuart, Thurman, Loy, and Batiste	2011	The United States	Structured survey	387 employers	Accommodations	This research found that satisfaction with accommodations is high, costs are minimal, positive financial outcomes, increased productivity and retention, and enhanced public image
Heera	2016	India	Literature review	44 articles		Found (1) previous experience with persons with disabilities leads to more favorable perception; (2) disability type impacts inclusion; (3) concerns over work performance; (4) fear of litigation; (5) decisions impacted by customer and coworker reactions; (6) concerned about the cost of hiring and accommodating; and (7) employer gender and education impact attitudes
Heera and Devi	2016	India	Literature review	44 studies		The authors found the following factors influence employers' perspectives on hiring persons with disabilities: (1) Previous experience with persons with disabilities creates more favorable perceptions (2) The type of disability has an impact on inclusion (3) Concerns over work performance are a factor (4) Concerns over possible legal ramifications

						(5) Concerns over customer and co-worker reactions (6) Concerns about the added cost of accommodation (7) Employers' level of education, gender, and organizational characteristics
Hemenway, King, Rohani, and Word	2003	The United States	Survey	306 employers		The authors found differences between the chamber of commerce and non-chamber groups, employers' lack of awareness of disability issues and resources, and employer attitudes toward individuals with disabilities
Henry, Petkauskos, Stanislawzyk, and Vogt	2014	The United States	Focus groups	51 employers, 16 community rehabilitation providers, 7 persons with disabilities		The employer saw stigma, uncertainties concerning applicants' abilities and the complexity of the public disability employment service system as hiring barriers They saw diversity, expanded talent, and improved brand loyalty as advantageous
Hernandez, Chen, Araten-Bergman, Levy, Kramer, and Rimmerman	2012	The United States	Theory of Planned Behavior, focus group	12 employers		The Theory of Planned Behavior can predict employers' intentions to hire persons with disabilities Not-for-profit organizations' attitudes are more favorable than those of for-profit organizations
Hernandez, Keys, and Balcazar	2000	The United States	Literature review	37 studies		Employers with prior positive contact have a favorable perception of employees with disabilities Willingness to hire still exceeds actual hiring There is a preferential hierarchy of disability

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Study	Year	Location	Methodology	Sample Size	Focus	Findings
						types The trend of a relationship between a positive perception of persons with disabilities and employers' level of academic achievement and company size is diminishing Employers are positive about employees placed by vocational, employment, and supported-employment programs
Hernandez, McDonald, Divilbiss, Horin, Velcoff, and Donoso	2008	The United States	Focus groups	21 employers	Health care, hospitality, and retail sectors	Five themes emerged: (1) the importance of disability employment agencies and disability advocates, (2) the persistence of manager bias, (3) the lack of promotional opportunities for persons with disabilities, (4) perceptions of costs associated with having employees with disabilities, and (5) there are benefits associated with hiring persons with disabilities (low absenteeism, long tenure, diversification, more positive work environment)
Houtenville and Kalargyrou	2012	The United States	Analysed 2008 ODEP Survey of Employer Perspectives on the Employment of People with Disabilities	320 hospitality companies	Hospitality and leisure sector	The study found prejudice and stereotyping, but the chief concern was the bottom line
Houtenville and Kalargyrou	2015	The United States	2008 ODEP Survey of Employer Perspectives on the	263 leisure and hospitality companies	Hospitality and leisure sector	Service-producing companies are more likely to hire than goods-producing companies Service companies with direct customer

			Employment of People with Disabilities			interaction are more likely to identify customer attitudes as a reason not to hire
Huang and Chen	2015	Taiwan	Interviews	12 employers		Four reasons for employing persons with disabilities were found: personal experience with a disability; cost-effectiveness due to reduced turnover; altruism and charitable perspectives (i.e., improved image CSR); and compliance with the quota Employers were more concerned with the recruitment stage than after hiring Once hired, they tended to focus on capabilities rather than limitations, training, and job match All employers agreed with accommodations The authors found limited career advancement opportunities for persons with disabilities
Hwa	2017	Malaysia	Survey	201 employers		Employers have different perceptions of employees with disabilities by gender, with more favorable perceptions toward women. They also have different perceptions of employees with disabilities based on the type of disability. Men with physical disabilities and women with auditory/communication details were viewed more favorably
Jasper and Waldhart	2013	The United States	Statistical analysis of 2008 ODEP Survey of Employer	320 leisure and hospitality companies	Leisure and hospitality	The authors found chief concerns were job performance and the cost of accommodation These were of more concern for smaller employers

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Study	Year	Location	Methodology	Sample Size	Focus	Findings
			Perspectives on the Employment of People with Disabilities Theory of Planned Behavior			The most appealing practices were positive employee and manager attitudes, job mentoring, and financial incentives
Jasper and Waldhart	2012	The United States	Statistical analysis of 2008 ODEP Survey of Employer Perspectives on the Employment of People with Disabilities Perceptions of Challenges Index		Retail	Employer size is a significant predictor of retailer perceptions of hiring people with disabilities
Ju, Zhang, and Pacha	2012	The United States	Survey	168 employers		The authors found that employers' four most valued employability skills (integrity/honesty, ability to follow instructions, respect for others, and timeliness) were the same for persons with disabilities and those without disabilities. A discrepancy arises with the fifth most valued employability skill, where employers value regard for safety for persons with disabilities vs. the ability to read with understanding for persons without disabilities Employers ranked all five skill areas the

						same Employers expect more skills from employees without disabilities Employers from the service business area had higher expectations regarding higher-order thinking skills, social skills, and personal traits Women had higher expectations regarding certain skills than male employers
Ju, Roberts, and Zhang	2013	The United States	Literature review	15 studies		The review found that employers showed more positive general attitudes toward employees with disabilities. Employers had concerns about specific types of disabilities. Positive past experience with persons with disabilities contributed to a greater willingness to hire. Employers expressed concerns over employability issues but expressed fewer issues and more benefits than in previous studies, and there was a greater realization of the low cost of accommodations
Kang	2013	Korea	Interview	20 human resource directors		The study makes several recommendations to government, including improving the job skills of persons with disabilities; decreasing employers' fears about industrial accidents for workers with disabilities; and supporting employing persons with disabilities through tax and social insurance breaks, a national campaign to alter people's attitudes, adjustments to quotas, providing a database

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Study	Year	Location	Methodology	Sample Size	Focus	Findings
						of job seekers with disabilities and strict enforcement of the quota system
Kaye, Jans, and Jones	2011	The United States	Survey of known ADA – recalcitrant employers	463 human resource professionals and managers		Chief barriers are a lack of awareness of disability and accommodation issues, cost perceptions, and fear of liability
Kulkarni and Lengnick-Hall	2014	The United States	Literature review			Obstacles identified in the literature may only represent partial reality due to the significant reliance on laboratory studies
Kocman, Fischer, Weber	2018	Austria	Mixed methods: semi-structured interviews, 3 questionnaires (disability-specific barriers questionnaire, community living attitude scale, ID-ability-questionnaire)	30 hiring managers	Intellectual disability	Perceive more problems and barriers in employing persons with intellectual disabilities and mental disorders than persons with physical disabilities
Lengnick-Hall, Gaunt, and Brooks	2001	The United States	Literature review			This research reviews several factors affecting the employment of persons with disabilities and how those perceptions are not based on evidence
Lindsay, Goodfellow, Stergiou-Kita, Kirsh and Lero	2013	Canada	Scoping review	61 studies		This research identifies promising policies, programs, and practices for service providers, employers, and policymakers For employers, it identifies the need for more employer awareness of disability, strong senior management commitment to the

						success of disability employment initiatives, and the need for employers to interface with service providers to provide expertise on integration and accommodation
Lindsay, Robinson, McDougall, Sanford, and Adams	2012	Canada	Survey	33 employers	Adolescents	This research found supervising youth with disability improved employers' perceptions concerning employing persons with disabilities
Lindsay, McDougall, and Sanford	2012	Canada	Survey	36 supervisors	Youth	The study focused on supervising rather than hiring Supervisors improved their assumptions concerning persons with disabilities after supervising youth with disabilities
Lindsay, Robinson, McDougall, Sanford, and Adams	2005	Canada	Survey Qualitative and quantitative	33 employers	Youth	This research identified some concerns about accommodations and workload Overall, employers had a positive experience supervising youth with disabilities
Loo	2002	Canada	Survey, Attitudes Toward Employing Persons with Disabilities and Marlow-Crowne Social Desirability Scale	231 management undergrads		This research found that there were positive attitudes towards employing persons with disabilities but also conflicting attitudes (i.e., organizations should not give special staffing consideration for persons with disabilities)
Loo	2004	Canada	Survey, MacLean and Gannon's Discomfort-	231 management undergrads		This research found that discomfort dimensions play a dominant role in attitudes toward employing persons with disabilities

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Study	Year	Location	Methodology	Sample Size	Focus	Findings
			Sympathy categories and Attitudes Toward Employing Persons with Disabilities and Interaction with Disabled Persons Scale			
Louvet	2007	France	Experimental	132 management undergrads 152 graduate business students		The study found a job fit effect; applicants with a disability were rated more negatively than nondisabled in poor fit conditions (i.e., requiring public contact or perceived as a typically male job) It also found that persons with disabilities were perceived to be warm but not competent
Luecking	2008	The United States	Literature review			Despite more enlightened views of disability, employers still hold confused and stereotypical views about employees with disabilities Usually, exposure to persons with disabilities improves employers' views, so the real barrier may be the lack of being prepared to support these employees Job developers need to refocus on demand-side concerns by being customer-oriented, focusing on understanding employers' needs and taking on a role more like an organizational consultant than a job finder, as well as providing post-placement

						services, being responsive to employer needs and focusing on improving employers' financial situation
Mak, Ho, and Kim	2014	Singapore	Theory of Planned Behavior and Social Cognitive Theory Quantitative 72-item online survey	145	Cancer	The strongest factors related to the intention to hire are efficacy, followed by attitude The strongest factors regarding retention were perceived moral obligation and attitude towards cancer
Mansour	2009	Saudi Arabia	Survey	27 employers		Perceived issues with productivity, work performance, and lack of employee skills were the top factors for not hiring persons with disabilities
Mansour	2009	Saudi Arabia	Questionnaire	27 companies		Employers' main concerns were productivity, work performance, and lack of skills and experience
Marques, Romeo, Matalinares, Yepes-Baldó	2020	Brazil	Survey-Disability Conceptions Inventory	257 managers		They found that managers had three conceptions of disability: spiritual conception, conception based on the assumption of normalcy, and conception based on the assumption of inclusion
McDonnall	2014	The United States	Survey 11-item attitude scale developed	158 in hiring positions	Blind	They found the instrument has criterion validity The authors found that some employers have negative attitudes toward visually impaired employees, and others have positive attitudes

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Study	Year	Location	Methodology	Sample Size	Focus	Findings
McDonnall, Antonelli	2019	The United States	Survey	388 hiring managers	Blind/visually impaired	Found prior communication with vocational rehabilitation, company size, company policy, receipt of an application, prior personal relationship with the visually impaired and employer attitudes were associated with hiring
McDonnall, Antonelli	2020	The United States	Experimental – pre, post, and 4-month follow-up. Random assignment to four conditions involving two interventions	59 hiring managers	Blind/visually impaired	A brief intervention consisting of a meeting with a vocational rehab professional can improve attitudes about this population. Improved attitude and knowledge were retained, although intent to hire was not retained on follow-up. Meeting with a blind vocational rehab professional did not increase the attitude and intent to hire. The educational approach vs. the dual customer approach increased knowledge somewhat
McDonnall, Cmar, Antonelli, Markoski	2019	The United States	Survey-implicit association test-blind/visually impaired	450 managers/supervisors, director/chief executive and human resource personnel	Blind/visually impaired	Found blind professionals have more positive implicit attitudes than employers. Employers had a stronger association between blindness and incompetence
McDonnall, Cruden, and Zhou	2013	The United States	Survey	183 rehabilitation counsellors and business relations staff	Blind/visually impaired	Vocational rehabilitation staff have a more negative view of employers' attitudes concerning the likelihood of employing blind or visually impaired employees than business relations staff

McDonnall, Lund	2020	The United States	Survey – including four Theory of Planned Behavior construct measures	388 hiring managers	Blind/visually impaired	Found intent to hire was affected most by employers’ attitudes about the productivity of persons who are blind, followed by subjective norms and perceive behavioral controls
McDonnall and O’Mally	2015	The United States	Survey	181 employers	Blind/visually impaired	The findings show that employers’ attitudes improve with contact with vocational rehabilitation agency personnel
McDonough, Ham, Brooke, Wehman, Wright, Godwin, Junod, Hurst	2021	The United States	Focus groups	27 executives	Health care	Found that these organizations’ faith-based missions and values align with employing persons with disabilities. These managers actively socialize with their staff and live their values. Entrenched in these beliefs is treating all employees as individuals who require tailored, unique employment solutions Organizations benefit from (1) employing persons with disabilities from a diversity target perspective, (2) work done better than other developing employees, and (3) their presence improves morale
Millington, Miller, Asner-Self, Linkowski	2003	The United States	Theoretical			While the article examines management functions through a vocational rehabilitation lens, it contributes by assessing the intersection of different management functions (staffing, planning, organizing, controlling, and directing)
Moon and Baker	2012	The United States	Delphi survey	44	Accommodations	There is a perception that employers fail to accommodate because they are unaware of the range of options or assume they are too expensive

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Study	Year	Location	Methodology	Sample Size	Focus	Findings
Morgan and Alexander	2005	The United States	Survey	534 employers		Most respondents with experience indicated that the employment usually or sometimes worked well, and they were likely to hire again. Many inexperienced respondents were also receptive to hiring. Experienced respondents identified advantages to employing individuals with disabilities at higher rates than inexperienced respondents
Murray	2014	Canada	Policy analysis and semi-structured interviews	3 employers		This research found variance in the application of the policies and less understanding of the policies in organizations without a human resource department. Interviews revealed employers' views of disability, knowledge, and application of the disability policies, the "fit" of a prospective employee, the importance of a human resources department, and the presence of accessibility in the workplace
Noor, Isa, Manaf	2018	Malaysia	Semi-structured interviews	6 employers		Hesitancy to hire persons with disabilities stems from a lack of exposure, and government supports for persons with disabilities is inadequate
Nota, Santili, Ginevera, and Soresi	2013	Italy	Experimental design – randomly assigned to two conditions, one where candidates presented the difficulties of their	80 employers		The authors found participants' attitudes were more negative concerning people with psychological problems than those with an intellectual disability or a sensory disability. All types of disabilities presented benefited from positive presentations of their disability

			disability and another where they discussed their positive aspects			
Olson, Cioffi, Yavanoff, and Mank	2001	The United States	Survey	126 HR personnel, managers and corporate executives		Employers perceive that employees with mental retardation have a positive impact on the workplace, except that they will require additional training and supervision
Paez and Arendt	2014	The United States	Survey	124 hotel and restaurant managers		Found a slightly positive attitude toward working with persons with disabilities
Papakonstantinou and Papadopoulos	2017	Europe	Test-retest after short information program	40 employers		Employers' behaviors can be modified by providing information
Peck and Kirkbride	2001	The United States	Review of rehabilitation strategies to respond to employers' fears about employing persons with disabilities			Employers' four main fears are the cost associated with hiring, the need for additional supervision and lost productivity, not being able to terminate a bad hire and concern over being stuck with an unqualified employee
Pearson, Ip, Hui, Ho, and Lo	2003	Hong Kong	Experimental Multiple pairwise comparison	409 job advertisements × 4 application letters each = application 1636 letters 331 responses		Found statistically significant preference for the non-disability group when compared with each of the disability groups. Found a clear ranking of preference; people without a disability, followed by those with a hearing impairment, those using crutches to walk and finally, those who had had depression

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Study	Year	Location	Methodology	Sample Size	Focus	Findings
Piramanayagam, Seal	2020	India	Questionnaire	31 managers	Hotel industry	Employers have positive attitudes toward persons with disabilities concerning employee loyalty, reliability, and work quality. They have negative attitudes concerning aesthetic anxiety, cost of training, extended supervision, lack of work experience, litigation, and time management
Popovich, Scherbaum, Scherbaum, and Polinko	2003	The United States	Survey Two studies without and one with the ADA definition of disability	118 undergraduates 147 undergraduates		Participants had little knowledge of what a disability is under the ADA Women favor more reasonable accommodations Experience with people with disabilities is associated with more positive affective reactions but not with more reasonable accommodations
Quesnel	n.d.	Canada	Local survey	30 persons with disabilities 62 employers		This research identifies that less than 50% of businesses surveyed hire persons with disabilities Those who did employ persons with disabilities only experienced minor challenges Most of those who had not employed persons with disabilities would not know how to attract them
Ren, Paetzold, and Colella	2008	The United States	Meta-analysis literature review	23 articles re experimental studies		Having a disability and especially a mental disability is causally connected to negative human resource judgments
Requero, Santos, Pareded, Brińol, Petty	2020	Spain	Experimental to assess meta-cognitive process	Study 1–65 undergraduate students		The study shows the connection between thought vallance and thought confidence. Higher thought confidence was more

			concerning attitudes toward people with disabilities	Study 2–264 undergraduate students		predictive of attitude towards persons with disabilities
Rooth (Abstract)	2009	Sweden	Field experiment		Obesity	Indications of obesity result in a significantly lower callback rate
Sālājeanu	2012	Holland	Interview	10 employers		Employers' willingness to hire persons with disabilities and actual practices differ
Schur, Kruse, and Blank	2005	The United States	Literature review Study corporate culture			Corporate commitment in and of itself is not sufficient. If supervisors and fellow employees do not accept disabled workers' disability, initiatives will fail. These attitudes are affected by stereotypes, discomfort in being around persons with disabilities, the strain caused by communication difficulties, personality, and prior experience with disabled persons
Scott, Jacob, Hendrie, Parsons, Girdler, Falkmer, Falkmer	2017	Australia	Survey	59 employers	Autism spectrum disorder	Employers demonstrated concerns over cost and work performance, but findings do not bear out those concerns. Larger organizations, previous experience, and collaboration between employers and disability employment services seem to have a more favorable view of employees with an autism spectrum disorder
Shamshiri-Petersen, Krogh	2020	Denmark	Experimental (vignette survey)	1901 managers	Physical disability	Intention to hire declines substantially when wheelchair use is introduced
Shankar et al.	2014	Canada	Interviews	28 employers	Mental illness	A high percentage of the employers were in favor of hiring persons with disabilities Previous negative experiences with an employee with mental illness may be a

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Study	Year	Location	Methodology	Sample Size	Focus	Findings
						barrier to employment Employers with positive experiences or who worked with employment placement providers have less prejudicial attitudes The findings suggest the need for support for frontline managers
Shaw	2013	Canada	Scoping review/ literature -review	38 evidence articles 19 gray literature		Four predominant barriers are identified: attitudinal barriers, employer barriers about performance, employers' lack of awareness of disability and managing disability, and lack of integration of services and policies to promote hiring
Shier, Graham, and Jones	2009	Canada	One-to-one semi-structured open-ended interviews and focus groups	Mixed methods 56 persons with a disability participating in employment training programs in Calgary and Regina		Persons with disabilities face extensive stigmatization and discrimination within the labor market Discrimination and labelling are the primary barriers
Stevens	2002	The United Kingdom	Survey	120 companies		Specific impairments seen as obstacles to employment are limited keyboard/writing ability and speech and vision impairment Important personal skills for successful work performance were seen as interpersonal social skills and the ability to handle information
Stone and Wright	2013	The United Kingdom	Experimental – Replied to job	144 companies		The study found recruitment discrimination against persons with facial disfigurement in

			postings with three CVs in three conditions (facial disfigurement, wheelchair and nondisabled)		Facial disfigurement, wheelchair users	jobs involving a greater degree of customer contact. Wheelchair users were treated unfavorably regardless of the amount of customer contact
Strindlund, Abrandt-Dahlgren, Ståhl	2018	Sweden	Semi-structured interviews	27 employers		Three categories of different views of employees with disabilities emerged. (1) Constrained by disability – lacked competence, work experience and personal characteristics, unreliable due to absenteeism, difficult to integrate, and lacking interest in the field. Other constraints were – a belief that accommodations could not compensate for reduced work capacity, the employer's high workload, limited human resources support, and a lack of knowledge about accommodations. Constraints due to suboptimal government cooperation (2) Employability as independent of disability – the right competence, experience, characteristics, will to work, and interest in the field were more important than disability limitations (3) Employability as conditional – employability was not predetermined by disability but context-dependent on a variety of factors Also, found cross-cutting themes of trust of persons with disabilities, that persons with

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Study	Year	Location	Methodology	Sample Size	Focus	Findings
						disabilities contribute to the workplace, and the availability and organization of support impacted employability
Ta, Wah, and Leng	2011	Malaysia	Survey	39 companies		Barriers to employing persons with disabilities are lack of knowledge and lack of experience in managing persons with disabilities. Employers perceive that they require more expense to supervise and train employees with disabilities. Most employers lack accessible environments
Unger	2002	The United States	Literature review	24 studies		The type and severity of disability may affect the likelihood of employment Employers may sacrifice productivity for dependability Employers recognize the potential to enhance their community image Employers with previous experience are more willing to employ persons with disabilities
Vornholt, Uitdweillgen, and Nijhuis	2013	The Netherlands	Literature review	48 articles		Employers see hiring persons with a disability as a risk and resist making reasonable accommodations. They are motivated by concerns over cost, safety, legal liability, or managerial biases. However, employers open to hiring who are characterized by openness to diversity and equality are also identified

Waterhouse, Kimberly, Jonas, and Glover	2010	Australia	Focus group	40 employers		Employers see their lack of knowledge, understanding and capability as the problem. They perceive difficulties in hiring persons with disabilities, and this creates barriers
Weigand	2008	The United States	Experimental Ranking 50 mock job applicants	3 students		Emphasis on work experience is the most significant influence on preference ratings Ratings are improved when a disability is presented in a positive way
Wilton and Schuer	2006	Canada	Semi-structured interview	46 employers		This research found: (1) some manufacturing employers are concerned about the feasibility of accommodating the physically disabled
Woodley and Metzger	2012	New Zealand	Mixed methods Interviews and survey	106		There is a hierarchy of disabilities that does impact employers' perceptions Perceptions about how staff and customers react may give social permission not to hire
Zappella	2015a	Italy	Literature review (Abstract only)			The findings synthesized around some broad categories: personal characteristics of employers (perceptions about the legislation, emotional reactions, obstacles, and concerns), characteristics of the organization (type of the activity and methods of recruitment), and characteristics of the worker (physical, intellectual, or acquired disabilities)
Zappella	2015c	Italy	Interviews Phenomenological approach	30	Intellectual disabilities	Found that decisions to hire were affected by (1) the personal characteristics of the employer concerning their concept of disability and past experience with persons with disabilities, (2) the selection process,

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Study	Year	Location	Methodology	Sample Size	Focus	Findings
						i.e., identification of tasks and whether candidates are assessed by the employer or a third party, evaluated for limitations or abilities, (3) concerns of the employer over the law, productivity, safety, and managing the employee's emotions
Zappella	2015b	Italy	Interviews Phenomenological approach Delphi	30	Small and medium-sized companies	"The results show that experience towards the employee with a disability are influenced by three important topics: the[re] previous experience, the [choice] of the tasks and the reasons that lead to the recruitment process."
Zissi, Rontos, Papgeorgiou, Pierrakou, and Chtouris	2007	Greece	Cross-sectional survey	102 employers		Employers' attitudes differ depending on the type of disability

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Economic Inclusion and Empowerment of People with Disabilities

63

Peter Blanck, Fitore Hyseni, and Nanette Goodman

Contents

Abstract

People with disabilities continue to face extreme disparities in economic inclusion. They have lower employment rates, earn significantly less, are more likely to engage in precarious work, report barriers to receiving workplace accommodations, avoid disclosure of invisible and stigmatized identities, and are more likely to report discrimination than their non-marginalized counterparts. These challenges are heightened by and interrelated with other inequalities that marginalized populations experience such as higher rates of poverty and lack of access to education, housing, transportation, medical care, banking, and food. The COVID-19 pandemic has amplified the employment disparities between people with and without disabilities and within the non-monolithic disability community. Many people with disabilities experienced job losses, lower earnings, and challenges getting access to adequate social support. This chapter discusses barriers to economic inclusion of people with disabilities. In particular, it focuses on employment and financial inclusion as two key markers of larger economic empowerment. In helping to illuminate the many complex issues faced in the employment of persons with disabilities, this chapter aims to identify new and

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promising means to address barriers faced by people with disabilities. With increased partnership and collaboration, with the disability community leading this effort, the public and private sectors must seek to address the employment of persons with disabilities, which affects millions in the United States and around the world.

Keywords

Disability · Employment · Workplace discrimination · Economic inclusion · Diversity · Equity · Inclusion

Introduction

People with disabilities continue to face extreme disparities in economic inclusion. The US Bureau of Labor Statistics data show that only one in three working-age people with disabilities (31.4%) were employed in 2021, as compared to three-quarters (72.5%) of their nondisabled peers (U.S. Bureau of Labor Statistics, 2022). This large chasm in employment exists despite studies showing that people with disabilities have similar qualifications and motivation for employment as people without disabilities (Ali et al., 2011).

Even when employed, people with disabilities earn, on average, significantly less per year than those without disabilities (Schur et al., 2013, 2020; Kruse et al., 2018). Due in large part to lower employment and earnings, people with disabilities are more than twice as likely to live in poverty (Goodman et al., 2019). People with disabilities and in particular those who embody other marginalized identities based on race, ethnicity, age, sexual orientation, and gender identity experience substantial employment and economic disparities beyond those faced more broadly by people without disabilities (Badgett et al., 2020; Blanck et al., 2020; BLS, 2022; Goodman et al., 2019; Medina et al., 2021).

The COVID-19 pandemic amplified the employment disparities between people with and without disabilities and within the non-monolithic disability community (Blanck, 2020). Many people with disabilities experienced job losses, lower earnings, and challenges getting access to adequate social support. The pandemic hit people with disabilities especially hard, resulting in initial substantial employment losses due largely to their greater prevalence in the most hard-hit industries and occupations such as construction and food services (BLS, 2022; Houtenville et al., 2021; Schur et al., 2021).

Evidence suggests that hourly, contingent, and lower-wage employees were more likely to be fired, furloughed, and suffer pandemic-related employment and economic decline (Schur et al., 2021). People with disabilities are almost twice as likely to fall into those employment categories (Harpur & Blanck, 2020; Schur, 2003). Although employment rates have seen an increase since August 2020 and have continued trending upward in 2022 (Houtenville et al., 2021), people with disabilities continue to experience low employment and labor force participation rates that exclude them from the financial mainstream.

This chapter provides a broad picture of economic inclusion of people with disabilities in the United States. Specifically, we focus on labor force participation as a crucial axis for the larger economic inclusion and empowerment of people with disabilities. We present emerging issues related to the employment of people with disabilities during the pandemic and potentially thereafter. We review existing research and evidence and situate it in the current post-pandemic context to establish a picture of how the future of economic inclusion may look for people with disabilities. We organize the evidence into three sections: employment disparities, financial inclusion, and attitudinal barriers. These sections overlap and are interrelated at different junctures. Nonetheless, we present them as separate sections to make the classification of evidence possible.

We use an intersectional lens to highlight how structural and attitudinal barriers to and opportunities for economic empowerment, employment, and meaningful workplace participation differ for marginalized populations. Finally, we discuss new approaches and recent research being conducted to address employment barriers faced by people with disabilities. We highlight collaborative efforts among members of the disability community, researchers, employers, activists, and other organizations as part of the two new employment policy and employer-focused Rehabilitation Research and Training Centers (RRTCs), funded by the National Institute of Disability, Independent Living, and Rehabilitation Research (NIDILRR), led by Syracuse University and Rutgers University, respectively.

Economic Inclusion Through an Intersectional Lens

Informed by recent calls for critical assessments of inequalities we adopt and prioritize an intersectional lens in presenting the evidence in this chapter. Intersectionality, as initially theorized by Professor Kimberly Crenshaw, is a nuanced view that an individual's lived experience is greater than the sum of their identities and that forms of inequality can and do operate together and exacerbate each other (Crenshaw, 1989, 1990). Intersectionality suggests that inequalities should be considered through an interactive rather than a mono-categorical lens. Intersectionality is not an additive, individual, or ranking approach to identity or inequality (Conejo, 2013). Rather, it is a paradigm or lens to identify and analyze systemic inequalities that diverse individuals face. These inequalities coalesce to create and further social oppression, and efforts are needed to address these inequalities by focusing on the complex processes that produce them (Conejo, 2013; Erevelles & Minear, 2010).

Intersectionality represents a corresponding paradigm shift in research, law, and policy that has prompted an enhanced focus on socio-economic inequalities and their underlying interconnections (Collins, 2019). The detailed use of intersectionality as a scientific orientation in studying employment of persons with disabilities, however, thus far is limited. In the existing literature that applies an intersectional lens, disability has received relatively little attention (Berghs & Dyson, 2022; Frederick & Shifrer, 2019; Mauldin, 2021; Naples et al., 2019). There is a dearth of information about the multi-identity experiences of marginalized communities along the axis of disability.

Existing empirical research on the inequalities people with disabilities face in employment and other areas of daily life has also had limited success in embracing the idea of intersectionality. Some researchers note the framing of disability as a "master status," a raceless, genderless, and heteronormative identity that dominates individual identity and validates other forms of oppression (Barnartt, 2013; Brooks, 2021; Conejo, 2013; Frederick & Shifrer, 2019; Stienstra, 2019). Others believe the historical lack of diversity within the disability movement and research community hinders research documenting the experiences of marginalized populations with disabilities (Frederick & Shifrer, 2019).

This chapter brings into discussion existing literature on economic inclusion of people with disabilities reflecting scholars that have taken steps to use intersectional approaches in studies of employment outcomes which recognize that disability identity coexists with other minoritized identities (Blanck et al., 2020, 2021; Brooks, 2021; Goodman et al., 2019; Hyseni et al., 2022; Maroto et al., 2019; Pettinicchio & Maroto, 2017; Schur et al., 2021; Sevak et al., 2015). In doing so, we recognize the effect of complex individual identities as well as group-level and systemic factors that create structural inequalities (Bowleg & Bauer, 2016; Goethals et al., 2015; Miles, 2019).

Labor Force Inclusion

People with disabilities continue to experience disparities in labor force participation as well as equal employment opportunities. The passing and subsequent amendment of the Americans with Disabilities Act (Americans with Disabilities Act Amendments Act of 2008 or ADAAA) as well as the impact of the Disability Rights Movement have had a positive influence in improving employment outcomes for people with disabilities (Blanck, 2020). Nonetheless, recent research shows that disparities in employment still exist.

At the same time, the COVID-19 pandemic has resulted in major and ongoing socio-economic changes shifting work norms, such as telecommuting. This may be a "silver lining" for some people with disabilities while it could further marginalize others, as Professor Schur and colleagues suggest (Schur et al., 2020). Next, we discuss recent research documenting the current disability employment gap and the role of the COVID-19 pandemic. Through an intersectional lens, we also consider the future of work post-pandemic for people with disabilities.

The Disability Employment Gap

As mentioned, studies consistently show that people with disabilities are less likely to be employed than those without disabilities. Working-age people with disabilities are less than half as likely to be employed as people without disabilities (BLS, 2022). Historically and prior to the pandemic, the employment gap between people with and without disabilities had increased over time up until 2015 (Lauer & Houtenville, 2018; Schur et al., 2021). The employment gap was reduced between 2015 and 2019 when people with disabilities saw bigger employment gains (4.0-point increase) compared to people without disabilities (2.4-point increase) (Schur et al., 2021).

This gap in employment rates between people with and without disabilities has persisted despite studies showing that people with disabilities have similar qualifications and motivation for employment as people without disabilities (Ali et al., 2011). Despite the employment gap, research shows that close to 80% of non-employed people with disabilities want to work (Ali et al., 2011), which is a comparable percentage to unemployed adults without disabilities (Bonaccio et al., 2020).

Among people with disabilities, those who embody multiple marginalized identities face more complicated and nuanced challenges to employment. Multiply marginalized people with disabilities report lower employment rates (Brooks, 2021; Ciprikis et al., 2020; Charlton et al., 2018; James et al., 2016; Leppel, 2021; Pettinicchio & Maroto, 2017). In 2021, among working-age individuals with disabilities, only 29% of women and 34% of men were employed compared with 68% of women and 79% of men without disabilities. Non-Hispanic Whites with and without disabilities had the highest employment rates relative to other races and ethnicities (BLS, 2022).

Research suggests that the relationship between sexual orientation, gender identity, race, age, and disability is complex (Blanck, 2020). The combined effect of disability and gender on employment is greatest for women of color with disabilities, yet the impact of disability alone is greater for men (Brooks, 2021; Maroto et al., 2019; Pettinicchio & Maroto, 2017; Sevak et al., 2015). Research on the employment outcomes of other marginalized groups of people with disabilities, including lesbian, gay, bisexual, transgender, queer, and individuals with other sexual or gender identities (LGBTQ+), demonstrates that these individuals also experience higher rates of unemployment relative to their counterparts (Blanck et al., 2021; Charlton et al., 2018; Ciprikis et al., 2020; Leppel, 2021; James et al., 2016).

These documented disparities highlight the complex ways multiple forms of oppression such as racism, sexism, ageism, and ableism coalesce to disadvantage some groups. In particular, for people of color (POC) who have disabilities, participating in the labor force remains particularly difficult. Lack of employment has clear implications for economic inclusion as it keeps groups of population who are already marginalized and experiencing other forms of oppression from becoming financially independent and empowered.

Disparities in Standard Employment

Even when people with disabilities gain employment, they are more likely to work in low-wage, part-time, gig work, or other contingent jobs (Harpur & Blanck, 2020; Schur, 2003; Schur et al., 2013). A recent study by Schur and Kruse (2021) shows that workers with disabilities are more likely than those without disabilities to be in precarious jobs. Among employed people with disabilities, Black women, Black men, and Hispanic men are more likely to engage in precarious work such as temporary jobs and gig work. Schur and Kruse argue that precarious work represents a double-edged sword for people with disabilities. While some might choose it due to the flexibility it provides, others resort to precarious jobs as they face discrimination in obtaining standard jobs.

Precarious and nonstandard jobs typically do not provide paid sick leave, family and medical leave, and other benefits held by people without disabilities in standard jobs (Harpur & Blanck, 2020; Kruse et al., 2022). Workers in precarious jobs have limited opportunities for advancement and few, if any, worker protections, albeit some state law protections which vary by state. They also are often not covered by state and federal employment laws that provide income and other protection for workers such as unemployment insurance and workers' compensation (Harpur & Blanck, 2020; Kruse et al., 2018). As a result, employees who are unable to work due to a workplace injury or recurring illness, not only lose income, but also do not collect transitional income benefits that workers displaced from standard employment receive. This disproportionately drives large numbers of the target population into poverty, decreasing their ability to be economically self-sufficient.

Working in jobs such as contingent, precarious, and gig jobs that do not have a safety net of paid sick or medical leave or options for remote work puts people with disabilities at higher risk compared to those in standard jobs. They are more likely to lose their jobs and salary and thus their economic independence (Kruse et al., 2022). People with disabilities have, on average, higher numbers of doctor's office and hospital visits than those without disabilities (Kruse, 1998). They also have lengthier periods before they can return to workplace when they are injured or ill (Smith et al., 2014). For those in precarious jobs without benefits, the stark choice often becomes to overlook their health or quit working, thus limiting the opportunities for people with disabilities to remain employed.

While precarious jobs are sometimes beneficial for people with disabilities who are seeking flexibility, generally they lack a safety net required by all employees. Given the higher representation of people with disabilities in these jobs, they are often placed in the margins of employment where job and thus economic security is unstable.

Disparate Effects of the COVID-19 Pandemic

The COVID-19 pandemic exacerbated the employment and economic well-being disparities between people with disabilities and their counterparts (Blanck, 2020, 2022). Research prior to the pandemic shows that people with disabilities were more likely to be laid off by employers when times were bad and expressed feelings of lower job security (Mitra & Kruse, 2016; Schur et al., 2009, 2017). Expectedly, the start of the COVID-19 pandemic saw the number of people with disabilities employed drop significantly (Houtenville et al., 2021). Consequently, the disability employment gap increased early in the pandemic (Schur et al., 2021). In particular, White and Black women with disabilities experienced relatively greater employment losses during the pandemic compared to White men without disabilities.

The pandemic hit people with disabilities especially hard for several reasons. First, their jobs were more likely to be in occupations most affected, such as construction and food services (Schur et al., 2021). Second, hourly, contingent, and low-wage employees were more likely to be fired or furloughed (Bartik et al., 2020) and people with disabilities were twice as likely to be in these work situations as people without disabilities (Harpur & Blanck, 2020; Schur, 2003). In addition, such nonstandard jobs were disproportionately eliminated due to the COVID-19 pandemic (Harpur & Blanck, 2020). Consequently, workers with disabilities were more likely to experience unemployment than workers without disabilities during the COVID-19 pandemic.

Third, during the pandemic many office workers experienced the shift to remote or hybrid work. However, this shift in norms fueled by safety concerns often did not translate to jobs for people with disabilities. While workers with disabilities were more likely than those without disabilities to be teleworking before the pandemic, they were less likely to be teleworking as a result of the pandemic. The existing occupational differences between people with and without disabilities account for most of this difference (Schur et al., 2020; Kruse et al., 2022).

Despite the initial increase in the employment gap in 2020, the tight labor market post-pandemic and the shifts in work culture presented some "silver linings" for workers with disabilities (Schur et al., 2020). The employment rate of people with disabilities increased during 2021 economic recovery, regaining the losses caused by the pandemic (BLS, 2022; Houtenville et al., 2021). Nonetheless, the disability employment gap has persisted. A substantial portion of the increased gap is explained by differential effects of the pandemic across occupations, as mentioned. The unexplained portion of the employment gap, however, may reflect the growing attitudinal and structural discrimination that people with disabilities experience in employment, especially those embodying multiple marginalized identities (Schur et al., 2021).

The pandemic not only highlighted the existing inequalities and barriers to economic inclusion experienced by people with disabilities, but in some cases, it exacerbated them. Such is the case for many multiply marginalized people with disabilities who saw their employment opportunities dwindle.

Financial Disparities

People with disabilities are more than twice as likely to live in poverty than those without disabilities (Goodman et al., 2019). Black, Indigenous, and people of color (BIPOC) and women with disabilities are more likely to live in poverty than their counterparts (Goodman et al., 2019; Maroto et al., 2019; Pettinicchio & Maroto, 2017). The relationship between poverty and disability is strongly circular. Poverty causes disability by limiting access to health care and preventive services, increasing the likelihood that a person lives and works in an environment that may adversely affect health. The stress of poverty, overcrowded and poor living conditions, and shaky nutrition, all impact health and ultimately create disabilities.

Thus, marginalized groups are overrepresented among people with disabilities. Older individuals, women, BIPOC, those with less than high school education, and those with low incomes are disproportionally represented among the population with disabilities (Courtney-Long et al., 2015; Lauer & Houtenville, 2018; Okoro et al., 2018; Varadaraj et al., 2021; Warner & Brown, 2011). LGBTQ+ individuals are more likely to report disabilities and poor mental health compared to their counterparts (Fredriksen-Goldsen et al., 2012; Medina et al., 2021; James et al., 2016; Mulcahy et al., 2022; Pharr & Batra, 2021). Disabilities are disproportionately represented in rural counties relative to metropolitan areas. Much of these disparities are explained by differences in socio-economic factors such as lower education, income, and employment, but they persist even after controlling for these factors (Rhubart & Monnat, 2022; von Reichert et al., 2014; Zhao et al., 2019).

At the same time, disability causes poverty by limiting access to employment and full inclusion in the economic mainstream. These economic challenges have profound impacts on the well-being of marginalized people affecting access to housing, medical care, banking, transportation, and food security (Goodman et al., 2019; Medina et al., 2021; Henly & Brucker, 2019). Adults with disabilities struggle to pay their bills on time, save money for the future, and make ends meet (Goodman et al., 2017).

The next section addresses financial disparities such as low wages and lack of access to financial institutions. It then considers the implications of such financial disparities for people with disabilities and in particular for those from marginalized communities.

Disparities in Earnings

Even when people with disabilities gain employment, they have lower earnings, less upward mobility, and fewer opportunities for social and vocational inclusion (Goodman et al., 2019). They have lower average pay levels compared to employee without disabilities (Schur et al., 2017; Kruse et al., 2018). In addition, they are more likely to work in low-wage, part-time, and other contingent jobs (Harpur & Blanck, 2020; Schur, 2003; Schur et al., 2013), where the disability pay gap is higher than in standard, full-time, and permanent jobs (Schur & Kruse, 2021).

The COVID-19 pandemic worsened the financial situation of people with disabilities. In particular, workers with disabilities experienced greater health and financial concerns (Gignac et al., 2021a; Pettinicchio et al., 2021). They also likely experienced higher work-related stress and unmet workplace accommodation needs (Kruse et al., 2022). These initial studies highlight the importance of documenting the potential differential impacts of the pandemic on marginalized populations. They also call into question the “we are all in this together” approach promoted during the COVID-19 pandemic, as this may obscure deep structural inequalities experienced by marginalized populations that put them at greater risk of poverty, unemployment, mass incarceration, and COVID-19 infection (Bowleg, 2020).

For multiply marginalized individuals, disability interacts with other axes of inequality to limit economic empowerment and create layers of oppression and discrimination (Blanck et al., 2021). For example, women and people of color with disabilities report lower total income than their counterparts (Maroto et al., 2019). Similarly, LGBTQ+ individuals with disabilities report lower income and higher economic insecurity than cisgender and heterosexual people (Badgett et al., 2020; James et al., 2016; Medina et al., 2021).

Due to the many documented labor market inequalities, people with disabilities also often rely on financial support from the government. Around two-thirds of working-age adults with disabilities participate in at least one type of benefits program compared to one-sixth of those without a disability (Morris & Goodman, 2021). Programs such as Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), and Medicaid health insurance are important for the well-being of people with disabilities. Millions of people with disabilities use these financial and benefit programs to receive medical care, supports, and services they need to live independently to the maximum of their capabilities (Morris & Goodman, 2021).

These programs, however, have proven to be advantageous and disadvantageous, depending on the individual situation. For example, even when people with disabilities are able to achieve and maintain gainful employment that is crucial for their economic inclusion, rules for public benefit programs may prevent them from working to their full capabilities and prevent them from saving to become more financially stable (Maestas, 2019; Morris & Goodman, 2021). One such example is the case of SSI recipients who are encouraged to seek work but their ability to purchase supports needed to return to work is limited (Morris & Goodman, 2021). This situation is complicated by increased costs associated with inflation as well as disability-related out-of-pocket costs, which are discussed in the next sections.

Disparities in earnings, whether due to unemployment, occupational differences, or restrictions from benefit programs, put people with disabilities on an unequal footing compared to their nondisabled counterparts. Low salaries and benefits limit economic independence and worsen other inequalities such as access to education, housing, and transportation (Goodman et al., 2019), compounding the barriers that people with disabilities experience.

Disparities in Financial Inclusion

Access to financial services is important for the full economic inclusion of people with disabilities. Persons with disabilities remain underserved by banks and financial institutions. Despite the passing of the ADA, physical and digital access to formal financial services is often limited. Data from 2019 show that the unbanked rate for working-age disabled households was 16.2% compared to the 4.5% unbanked rate for working-age nondisabled households (FDIC, 2019).

Financial exclusion of people with disabilities is made worse by the high unemployment rates brought on by the employment constraints addressed in this chapter, as well as by low financial literacy levels, and inaccessible information provided by financial institutions (Goodman et al., 2019). One recent study by the Southeast ADA Center showed that many of the people with disabilities surveyed reported that they felt unwelcomed or disrespected by bank employees. More than half of the participants reported that their bank branch building was physically inaccessible. They also reported that mobile or internet banking apps, ATMs, and telephone banking options were not accessible to them (Whaley et al., 2022).

These challenges are intensified for those who are multiply marginalized and have disabilities. In particular, people with disabilities who are also Black and Hispanic report higher unbanked rates compared to non-Hispanic White and Asian people. These two groups also have the highest rate of using alternative and often predatory lending services (Goodman et al., 2019). These disparities highlight the compounding and unique effect of racism and ableism in shaping access to financial institutions.

Extra Out-of-Pocket Costs of Disability

Although government programs provide some economic support for people with disabilities, having a disability creates additional out-of-pocket costs for people and can limit their economic opportunities. These costs include medical and pharmaceutical treatment, mobility equipment or assistive technologies, and caregiving services essential for them to participate independently in the society and often live independently. These expenses that are incurred by people with disabilities but not by nondisabled peers worsen the economic situation of people with disabilities.

One recent study shows that adjusting the poverty rate to account for the direct additional costs of disability increases the rate from 24% to 35% (Morris et al., 2021). This would result in an estimated 2.2 million more people with disabilities counted as poor (Morris et al., 2021). These annual costs were estimated to be $18,322, and that would require, on average, 29% more income for households with a person with a disability to obtain the same standard of living as households without a member with a disability (Morris et al., 2021).

The existing barriers to economic inclusion, such as disparities in labor force participation, earnings, and occupation status, interact with other systems of oppression to often push people with disabilities into poverty. Despite this interaction between poverty and disability, governmental social service systems often consider them as separate issues (Morris & Goodman, 2021). For instance, receiving disability benefits frequently requires demonstrating that one is unable to work, while anti-poverty programs require that you participate in the labor force. As such, people with disabilities living in poverty are often faced with conflicting information or a lack of options to improve their economic situation.

Attitudinal Barriers

People with disabilities continue to face attitudinal barriers and stigma in all facets of their lives (Blanck, 2020). While we recognize that these broader challenges of discrimination impact the economic inclusion of people with disabilities, in line with the focus of this chapter, we examine the pernicious attitudinal barriers too often experienced in employment by people with disabilities.

Employer discriminatory attitudes and toxic organizational cultures can hinder employment of people with disabilities and thus serve as a barrier to economic inclusion (Blanck, 2020; Schur et al., 2014). Workplace culture that is unwelcoming discourages marginalized workers with disabilities from getting or keeping a job

(Araten-Bergman, 2016; Dimoff & Kelloway, 2019; Hanisch et al., 2016; von Schrader et al., 2014).

This section overviews the experience of workers with disabilities and the workplace barriers they face such as attitudinal discrimination and access to workplace accommodations. It then discusses emerging issues in labor studies such as the use of automated decision making (ADM) and algorithms in the workplace and the implications for the economic inclusion of people with disabilities.

Discrimination

People with disabilities face a variety of barriers from employers in getting and keeping a job. At the hiring stage, they typically encounter unfounded stereotypes and discrimination regarding their ability to work (Baert, 2018; Ameri et al., 2018; Blanck, 2020; Kaye et al., 2011). Employer audit studies show that employers are less interested in job applicants with disabilities, even when their resumes are identical to those of applicants without disabilities. These findings persist even in cases where one's disability is irrelevant to required job tasks and performance (Ameri et al., 2018; Baert, 2018).

Research suggests that this type of discrimination may be due to interviewers and managers being unaware of or untrained in best practices in hiring, mentoring, accommodating, and working with people with disabilities (Blanck et al., 2020). Another reported barrier that often discourages individuals with disabilities in the hiring stage is a lack of commitment, inclusive language, and targeted recruitment efforts (Araten-Bergman, 2016; Ball et al., 2005).

Once employed, many workers with disabilities face attitudinal barriers such as discrimination as well as more subtle biases such as low expectations from managers, supervisors, and co-workers. These barriers limit opportunities for career development and positive workplace experiences for people with disabilities (Schur et al., 2017). The prevalent ableism, sexism, ageism, and racism, coupled with other forms of oppression, often result in overt and more subtle (sometimes called "unconscious") workplace discrimination (Blanck et al., 2021). Marginalized employees with disabilities are more likely to experience and report discrimination in the workplace (Blanck et al., 2021; Dispenza et al., 2018; Jones et al., 2018; McMahon et al., 2012; Medina et al., 2021; Shaw et al., 2012). Despite having similar levels of organizational commitment and turnover intention as workers without disabilities, workers with disabilities have lower job satisfaction due to attitudinal barriers they experience in the workplace (Schur et al., 2017).

Discrimination in the hiring stage serves as gatekeeping to labor force participation for people with disabilities. As such, it limits their access to gainful employment and economic independence. Whether it is explicit discrimination, subtle discrimination, or lack of knowledge on how to be inclusive, employers may put candidates with disabilities at a disadvantage through their discriminatory treatment.

Workplace Accommodations

Workplace accommodations are individualized modifications to how the job is performed or the work environment itself. By addressing employment barriers, accommodations are essential in allowing qualified people with disabilities to join the labor market and fully engage and participate in job functions (Blanck, 2020). Studies by our research team and those of others show receipt of accommodations is positively associated with job tenure, higher job performance, and work-life satisfaction (Anand & Sevak, 2017; Blanck, 2020; Maestas et al., 2019).

Nonetheless, effective accommodations are not always available to all workers. Access to workplace accommodations remains a barrier to employees with disabilities (Schur et al., 2014; Anand & Sevak, 2017; Blanck et al., 2020; Dong, 2018; McDowell & Fossey, 2015). One prior study of accommodations by Blanck and colleagues provides a pre-COVID-19 baseline of workplace experiences, showing those who need accommodations most receive them less often (Blanck et al., 2020). Another study focusing on a nationally representative sample found that 47–58% of accommodation-sensitive individuals lack accommodation and that such accommodation would enable them to join the workforce (Maestas et al., 2019).

Workers with less visible disabilities (Anand & Sevak, 2017; Blanck et al., 2020; McDowell & Fossey, 2015; Dong, 2018) and those with multiple marginalized identities (Blanck et al., 2020; Hill et al., 2016) are least likely to access needed accommodations. Individuals with less visible disabilities and other marginalized identities may not request workplace accommodations due to the potential for discrimination associated with disclosure (Hickox & Case, 2020; Logue & Blanck, 2020; Hyseni et al., 2022). One recent study of legal professionals showed that women, young people, and parents are less likely to disclose disabilities (Hyseni et al., 2022).

Stigma and discrimination associated with mental health and less visible condition is widely documented (Blanck, 2020). To avoid stigma and discrimination, individuals with invisible and stigmatized disabilities and health conditions often choose to forgo disclosing their disability and requesting accommodations (Dewa, 2014). In particular, stereotypical perceptions of mental health have implications on what accommodations are viewed as “reasonable” (Telwatte et al., 2017).

Another major barrier to accessing accommodations for people with disabilities remains the lack of adequate and practical information and self-advocacy (Gignac et al., 2021). Many employees are not familiar with workplace accommodations (Price et al., 2017), especially those who have invisible disabilities. Many others with chronic health conditions such as addiction do not know they are recognized as having an ADA-covered disability, and others may now be recognizing the first signs and symptoms of mental health conditions (Hudson et al., 2016), making it difficult to know if they can request accommodations and what types of accommodations to request.

Lack of workplace accommodations creates a unique barrier for people with disabilities when it comes to maintaining gainful employment. Successful participation in the labor force is often contingent on these accommodations being provided. As such, when accommodations are not granted, they put people with disabilities at a disadvantage that impacts their economic security. The challenges in receiving accommodations are further heightened for marginalized workers (Hyseni et al., 2022). For those embodying other marginalized identities, disclosing and requesting workplace accommodations means an increased risk of experiencing additional discrimination.

Emerging Issues-Algorithmic Hiring

Discussions of discrimination have become more complex due to the growing use of algorithms and artificial intelligence (AI) in hiring and other decision making (Harpur et al., 2022). While AI is often proclaimed as a solution to reducing workplace discrimination by reducing human judgment, research shows that algorithms and the use of AI remain flawed in many respects and may lead to unfair outcomes in employment if not carefully considered.

These concerns were heightened during COVID-19 and its aftermath, due to widespread health-related data collection in the workplace that impacted worker privacy and employment opportunities (Harpur et al., 2022). Workers with disabilities have been put at an increased risk for discrimination due to either forced disability disclosure or "data mining" that makes their disability known to the employer.

The US Equal Employment Opportunity Commission (EEOC) is responsible for enforcing federal laws that make it illegal to discriminate against an employee because of race, religion, sex, national origin, age, disability, and genetic information. While the EEOC provides guidelines on the applicability of the ADA for algorithmic discrimination and intersectionality, this guidance typically is not legally binding (EEOC, 2022). Courts have applied different practices to intersectionality in their rulings, and plaintiffs have struggled to prove claims of intersectional discrimination (Abrokwa, 2018; Mazaheri & Bonano, 2022).

The wide use of algorithms in the workplace, such as for hiring, promotions, and monitoring the conditions of work, puts people with disabilities at an increased risk for disparate outcomes, for example, should they not be effectively accommodated (Harpur et al., 2022). The overall prevalence of workplace attitudinal and structural discrimination against people with disabilities cautions employers in using AI and automation in decision making. If unchecked, increased automation and data collection may unjustly and unknowingly discriminate against otherwise qualified people with disabilities, thus acting to reduce their opportunities for equal participation in the labor force and limiting their economic inclusion.

Paths Forward

Two new RRTCs led by Syracuse and Rutgers Universities are working to address many of the barriers identified in this chapter prior and to enhance the economic inclusion of persons with disabilities. These two national centers aim to directly inform the disability community, and employment and employer policies and practices to improve labor outcomes for people with disabilities. In this section, we overview areas for new research emanating from these centers and possible paths forward to promote economic empowerment.

Millions of individuals with disabilities become dislocated from work due to increasing severity of disability and new medical conditions. As a result, this group of individuals becomes connected to Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) systems for income support and critical public benefits such as health care. In challenging economic times, they are also more likely than people without disabilities to be laid off and receive Unemployment Insurance (UI) and/or apply for SSDI (Maestas et al., 2021). A recent study from scholars from the RRTCs shows that this was not the case during the COVID-19 pandemic (Mullen & Maestas, 2022).

Under the right conditions, many individuals have the potential and desire to make a successful return to the workforce. Three recent research studies illustrate our examination of ways to enhance opportunities for return to work. Specifically, they examine policies that promote a successful return to work from SSDI (including the impact of the Affordable Care Act, and state investments in home- and community-based services); policies to improve benefits counseling integrated with financial coaching to significantly promote a return to work from SSDI; and policies to enhance temporary increases in UI resulting from the COVID-19 pandemic (e.g., the important role that UI can have in helping people with disabilities sustain income and be able to return to employment).

We have overviewed that people with disabilities confront obstacles in obtaining employment, including from stereotypes, discrimination, insufficient accommodations, and lack of best practices, as well as in obtaining competitively meaningful "good" jobs. Future research coming from the RRTCs will consider: (1) expansion of the work activities of people with disabilities in the gig economy, who often have insecure contingent or nonstandard jobs, and how effective policy can improve this situation; (2) expansion of non-traditional routes to employment, such as in Disability-Owned Business Enterprises ("DOBEs") as locally based suppliers to corporations and governments, and to create niche opportunities for people with disabilities to demonstrate their abilities; and (3) expansion of proven apprenticeships, which is a core path to employment presently of renewed importance to promote economic advancement and employment for people with disabilities. These efforts will pay particular attention to increasing access to employment opportunities to marginalized groups.

Even when people with disabilities obtain employment via these strategies, however, they encounter challenges that can make it difficult to earn a living wage above poverty levels and retain employment. The RRTC researchers are exploring ways post-pandemic policy and practice changes can improve economic well-being of people with disabilities. For example, we are assessing the impact of increased wages of people with disabilities as a result of state policies that raise minimum wage rates above the federal level and state programs that eliminate subminimum wage levels for people with significant disabilities.

We are also investigating how paid leave benefits people with disabilities and helps them retain employment (e.g., particularly paid sick leave and paid family and medical leave). Finally, with workplace norms changing, we are examining the expansion of telework and remote work as triggered by the COVID-19 crisis. We are closely investigating the importance and effects of home-based work for people with disabilities, who are already more likely than those without disabilities to work from home and who can reap the benefits of flexible scheduling, individualized accommodations, and "natural" home-based supports.

As identified by extant research, individuals with disabilities experience extreme difficulties obtaining jobs, disparities in job outcomes once employed, discrimination, and insufficient workplace accommodations and are at greater risk of losing their jobs compared to their counterparts without disabilities. Adopting new governmental and employer policies and practices that target hiring and retention of people with disabilities, provision of effective accommodations, and increasing inclusion and support within the organization may help to significantly reduce these barriers to successful employment. However, employers lack clear best-practice frameworks and metrics to address these barriers. Our RRTC researchers are working to systematically identify, using quasi-experimental evidence, the effects of employer disability practices at large and smaller organizations on hiring, career advancement, retention, wage, and accommodation levels of people with disabilities.

As also discussed, people with disabilities face employment obstacles, including finding support and allies within organizations once employed. The importance of addressing these challenges and opportunities is more pertinent today because the COVID-19 pandemic has generally increased workers' stress and anxiety and has necessitated changes in the workplace such as telework and more reliance on individual technology.

Therefore, we are examining the effectiveness of signaling manager and co-worker acceptance and inclusion in hiring to build trust in people with disabilities, in an effort to help employers create better hiring process that is inclusive of people with disabilities. In addition, given the increased incidence of mental health disabilities post-pandemic, our RRTC team is working to enhance the use of workplace accommodations through supervisor and employee targeted information and workshops to increase knowledge on self-advocacy and appropriate disclosure in support of effective accommodations such as individualized digital accessibility and supervisor supports. These trainings will provide information to employers and employees on the unique challenges experienced by multiply marginalized workers with mental health disabilities.

Finally, challenges that workers with disabilities face are shaped by industry and organizational type and size and by changing job tasks. Practices used by large businesses in office settings often are not adaptable or successful in addressing barriers for other types of smaller organizations. Working with our partners, through qualitative and quantitative research, the RRTC researchers are systematically identifying best practices to increase employment and retention of employees with disabilities and other under-represented diverse groups in smaller businesses. To improve employment outcomes of people with disabilities across labor sectors, especially in those with a higher representation of minority and marginalized groups, the RRTC studies are documenting best practices for workers with disabilities in the healthcare industry, for example, having a high concentration of workers with disabilities, with a close study of the effects of the COVID-19 pandemic and intersectional dimensions and workers' experiences.

Conclusion

Ongoing studies show that the economic inclusion of individuals with disabilities remains elusive and, if not addressed, will continue to be a major societal challenge. Many individuals with disabilities still experience serious and systemic challenges in accessing financial resources and services that would allow for greater economic self-sufficiency. Discrimination and bias in the workplace remain prevalent and access to workplace accommodations remains limited for those with stigmatized disabilities such as mental health conditions and for those with multiple marginalized identities. Finally, employment rates remain low for individuals with disabilities from marginalized communities, especially along the axis of race.

In helping to illuminate the many complex issues faced in the employment of persons with disabilities, this chapter aimed to identify new and promising means to address this societal challenge. With increased partnership and collaboration, with the disability community leading this effort, the public and private sectors must seek to address the employment of persons with disabilities, which affects millions in the United States and around the world.

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Part X

Disability, Ethics, and Law

Disability, Ethics, and Law: Introduction

64

Francisco J. Bariffi and Gerard Quinn

Contents

Abstract

This section explores the intersection between disability, law, and ethics, and anticipates the challenges that the twenty-first century will bring. This brief introduction aims to anticipate key issues and significant challenges as the twenty-first century unfolds. To some extent, these are long-standing challenges. But many take on new forms, especially as medical and other technologies evolve exponentially. Evolving medical and technological advancements ignite a new ethical discussion regarding the risks and opportunities offered by disruptive technologies such as genetic engineering, neurotechnologies, or AI systems. Accordingly, this section is about the coming revolution – which is widely expected to occur – and the new legal framework required to regulate it from a disability rights perspective.

Introduction

This section of the book gets at the intersection between disability (law and policy) with ethics. It aims to be forward-looking and to anticipate flashpoints and significant challenges as the twenty-first century beckons. To some extent, these are long-

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standing challenges. But many are given new expressions, especially as medical and other technologies evolve exponentially.

The story of human evolution has been well-captured by authoritative commentators such as Yuval Harari et al. (2015). This story concerns the emergence of civilization from hunter-gathers into organized communities that can tackle common problems by combining resources and the mastery of tools to control nature. This accelerated during the Industrial Revolution to the point that humankind now has the power to control nature and destroy it and even life itself. The next phase will be even more telling and challenging. While humanity has used technology so far to control its environment, the next step will entail using technology and associated biomedical insights to change the nature of man himself.

We live in a digital revolution, which refers to the profound and widespread changes brought about by the advancement of digital technology. It has transformed our lives, including how we communicate, work, learn, and access information (Stibel, 2013). The digital revolution is like a massive shift from analogue to digital. Previously, information, such as text, images, and sounds, was stored and processed in analogue formats, like physical books, film negatives, or vinyl records. However, with the digital revolution, this information is now converted into digital form, represented as binary code consisting of 0s and 1s (Isaacson, 2014).

This technological development was triggered by the vertiginous evolution of interconnected computers and their use in neuroscience, genetics, robotics, and artificial intelligence (Bostrom, 2013; Kelly, 2016; Venter, 2013). Some authors have described this phenomenon as a new Renaissance (Goldin & Kutarna, 2017), as a new age in human history (Reese, 2018), or as the era of singularity (Kurzweil, 2005).

In this context, a new scenario of human-machine integration becomes a reality. It refers to combining or merging human abilities and actions with machines or technology (Schwab, 2017). Overall, human-machine integration aims to combine the strengths of humans and machines to enhance productivity, efficiency, and quality of life. By working together, humans and machines can accomplish tasks that neither can achieve alone, leading to new possibilities and improved outcomes in various domains (Kelly, 1994). Conversely, human-machine integration raises several ethical and legal dilemmas, most of which remain unanswered.

New techniques are emerging in neuroscience to “reveal” the person behind the mask of even those in persistent vegetative states (Fins, 2015). Neuroscientists are now beginning to talk openly about emerging technologies to, merge minds, i.e., integrating the human brain with advanced technologies to enhance or expand cognitive abilities and establish direct communication between brains (Mangan, 2018). This breakthrough has been possible with brain-computer interfaces (BCIs) development. BCIs are devices or systems that establish a direct connection between the brain and an external device, allowing bidirectional communication. BCIs could potentially enable direct communication between two or more brains. This could involve sharing thoughts, emotions, or sensory experiences among individuals. By establishing a direct neural link, people could communicate without needing verbal or written language. Additionally, new techniques and technologies are being discussed to enhance a person's cognitive abilities and potentially download a person's mind before expiration (Kaku, 2014).

Deep brain stimulation (DBS) is a neurosurgical procedure involving the placement of a medical device called a neurostimulator which sends electrical impulses, through implanted electrodes, to specific targets in the brain. While this technique is currently used for brain movement disorders, there is no technological impediment to its potential use in controlling antisocial human behavior (Farah & Wolpe, 2004).

Transcranial magnetic stimulation (TMS) is a form of brain stimulation in which a changing magnetic field is used to cause electric current at a specific brain area through electromagnetic induction. This technique is said to have shown diagnostic and therapeutic potential in mental health treatment. However, does this innovation offer a fundamental change in psychiatric intervention, or is it just an updated "electroshock treatment" form?

Optogenetics is a technique in neuroscience in which genes for light-sensitive proteins are introduced into specific types of brain cells to monitor and control their activity precisely using light signals. This technique is said to have led to insights into autism, schizophrenia, anxiety, or depression.

In sum, neurotechnology development is giving rise to ethical and legal dilemmas. The possibility of intervening in the brain to enhance its state, select individuals, erase fragments of memory, prevent behaviors, or determine if we are telling the truth is being raised. Neuroethics focuses on what is right or wrong regarding the treatment, enhancement, or manipulation of the human brain. What is specific to neuroethics compared to classical bioethical issues is that it questions the very definition of what is human. It addresses the ethics of neuroscience (such as regulating its advances, determining limits, and understanding their implications) and the neuroscience of ethics (how we construct moral principles and how our consciousness works).

There is enormous potential for states, companies, and non-state actors to infringe upon human rights through the misuse or abuse of neurotechnology. For this reason, a new approach toward the legal protection of the human brain is gaining wide acceptance. Neurorights refer to a set of rights and ethical principles aimed at protecting individuals' privacy, autonomy, and dignity in the context of advancements in neuroscience and neurotechnology. These rights address the ethical, legal, and social implications that arise from our increasing understanding of the brain and our ability to intervene and interact with it (Neurorights Foundation, 2022).

The development of modern biology and the study of the human genome has opened the doors to genetic manipulation, which makes it possible to create, edit, or discard embryos according to the expectations or wishes of the parents (Mukherjee, 2017; Ridley, 2000). The development of neuroscience has allowed us to know not only the physical-chemical functioning of the human mind but also its potential manipulation to influence the individual's behavior (Eagleman, 2017; Sapolsky, 2017). Algorithms govern what we know as "big data" and impact the searches and preferences of all users of digital content online (Bartlett, 2018; O'Neil, 2018). Artificial intelligence has replaced human intelligence in critical tasks in producing goods and services and in the free movement of people (Tegmark, 2017; West, 2018).

Significant shifts in technological growth with direct consequences in daily life conversely pose major ethical and legal questions, significantly when the rate of change has been growing exponentially. Let's think briefly about what these breakthroughs could accomplish in improving human life.

Gene editing using the so-called CRISPR method can be used to identify cures for many human genetic diseases. CRISPR (clustered regularly interspaced short palindromic repeats) is a revolutionary gene-editing tool that allows scientists to make precise changes to the DNA of living organisms, including plants, animals, and even humans. It's like a pair of molecular scissors that can cut DNA at specific locations and then change the genetic code (Carrey, 2019). As leading experts assert, "Now that science has a cheap and easy-to-use genetic editing tool at its fingertips, we could soon see the rise of precise genetic therapies that usher in a new era of medicine" (Doudna & Sternberg, 2018). Conversely, what could prevent gene editing from being used for choosing a baby's gender or implanting genes associated with desirable characteristics? (Rochman, 2018).

Prenatal genetic diagnosis (PGD) techniques allow the current medical practice to test embryos to detect the most common fetal chromosomal abnormalities. The natural question that follows is what could/should be done if such chromosomal abnormalities were to be detected. Is the purpose of these techniques to fix abnormal embryos or to discharge them (Parens & Asch, 2000)?

In 2015 the Council of Europe organized an International Conference on "Emerging Technologies and Human Rights" to identify priority human rights challenges raised by emerging technologies and their convergence while proposing interdisciplinary debate. The gathering concluded, *inter alia*, that science and technology have a growing impact on society, and it should be dealt with as a matter of priority; that convergence brings together the medical and nonmedical fields; and that the current legal framework is inadequate to address issues that are constantly evolving (COE, 2015).

In this respect, the "Rathenau Report" stresses that emerging technologies are seen to go beyond therapy and healthcare, blurring boundaries between medical/nonmedical applications and between health/illness. The scenarios outlined are generally complex, uncertain, and likely to reach an unpredictable (for some aspects imaginable, for others unimaginable) benefit/risk balance between individuals and society and present and future generations. That's why the question of safety (physical and mental integrity), individual privacy, and social acceptability is generally at the center of discussion. Still, there is another ethical challenge at stake: the challenge of justice (Van Est et al., 2014).

Consequently, a huge debate is on the table which clearly transcends the boundaries of biomedical innovations to social and military domains. It is not necessary to be an expert philosopher or rights advocate to easily understand that these innovations raise fundamental ethical and legal questions in relation to any existing domestic, regional, or international human rights protection framework. Let's think, for example, about the implications of gene editing in relation to the protection of the right to life, to equality and nondiscrimination, or to health or the implications of deep brain stimulation in the protection of the right to physical and mental integrity, the right to identity, or the right to autonomy and freedom of thought and belief.

While these technological innovations pose a threat to the general human rights discourse, they become particularly challenging in the context of disability rights (Quinn et al., 2016). Over a decade ago (2006) the United Nations approved the Convention on the Rights of Persons with Disabilities (CRPD) which is said to have adopted the so-called social model of disability (Bantekas et al., 2018). This transcendental legal body is considered the greatest motor for the paradigm shift from the medical to a social model of disability, and it has been able to establish as a binding obligation a series of legal standards to eliminate systematic discrimination that persons with disabilities face in their daily life.

The CRPD has become, in a surprisingly short time, a universal reference legal instrument, especially in the European context. The treaty has been signed, ratified, and implemented at the domestic level for nearly all Member States and ratified and implemented by the Union according to its international legal capacity. Likewise, for the Council of Europe, the CRPD has played and still plays a crucial role in interpreting human rights obligations in the context of disability rights.

Therefore, in this complex and unstable balance between progress and respect for human dignity, we must add a new element of consideration: "human diversity." The social model of disability has been, at its core, a critique of the status quo. And by doing so has evolved as a natural motor to challenge social structures, legal practices, and ethical thinking.

The ongoing influx of the physical sciences into the biological sciences goes hand in hand with a growing influence of an engineering approach to life. Therefore, the "biology becoming technology" trend implies and promises a strong increase in new interventions into living organisms, including the human body and brain (Van Est et al., 2014).

If we consider all these innovations described above and try to find a common feature or link between them, the answer becomes more evident. Science is on the quest to intervene in human evolution by selecting, modifying, or correcting abnormal physical and mental traits. Conversely, the modern notion of disability, i.e., the result of social barriers that hinder persons with physical, mental, intellectual, or sensorial impairments from enjoying equality of opportunities in life, actually includes those persons with "abnormal physical and mental traits" for rights protection purposes.

Consequently, could science fix disabling impairments? Or, instead, could this new impairment-fix scenario could allow the rebirth of the medical model of disability and, accordingly, a shift backwards on disability rights recognition and enjoyment? Will the future foresee the birth of a new human/artificial category?

Overall, the debate surrounding the impact of technology on the rights of people with disabilities ultimately revolves around the concept or definition of disability itself. The prevailing social model distinguishes between impairment (a personal element) and barriers (a social element). Agustina Palacios argues that disability has at least three dimensions. The first is the condition of disability, which is the personal dimension. How this condition is defined and conceived undoubtedly affects a person's identity. If the perspective arises exclusively from a medical diagnosis, such as impairment, it becomes an identity of insufficiency and a lack of autonomy. The second dimension to consider is the situation of disability; the interrelational, situational, and dynamic dimension arises when social barriers come into play. This situation is what truly "disables," restricts, and/or prevents the exercise of rights on equal terms with others. It has been highlighted by political activism and the social model of disability since the 1970s. The third dimension is the position of disability, which is structural. It resides in representations, evaluations, and culture, resulting from our prejudices and stereotypes (Palacios, 2020).

The condition of disability is related to impairment, while the situation and position are related to social barriers. The condition of disability cannot be a requirement or reason for exclusion in the enjoyment and exercise of rights, as that would be discriminatory.

However, the distinction between the condition and situation of disability, or in other words, between impairment and barriers, brings a new ethical debate to light regarding the risks and opportunities offered by disruptive technologies such as genetic engineering, neurotechnologies, or AI systems. On the one hand, technology offers tools to correct or eliminate disabling impairments, and on the other hand, it offers tools to remove various barriers. Unlike predecessor technology (primarily analogy), AI-based technology (digital) enables predictive schemes that potentially impact human biology. In other words, AI-based technologies offer, for the first time, the possibility to modify a person's cellular and neurological structure to restore sensory and cognitive functionalities that virtually eliminate the impairment or condition of disability (Bariffi, 2021).

Nevertheless, when we think about the relationship between technological development and disability, we cannot ignore the historical fact. Science has frequently been used to justify and implement eugenic practices, concealment, marginalization, institutionalization, and medical experimentation (Bariffi, 2018).

Undoubtedly, technology has allowed certain groups within the disability community to access greater rights and better opportunities. From the very beginning of the medical model, technology has provided individuals with sensory and motor impairments with a tool for social integration. However, it is known that this approach only allowed the integration of a tiny minority while promoting the exclusion of people with disabilities from society. It is often said that the medical model was more a model of institutionalization (psychiatric institutions, rehabilitation centers, education, employment, etc.) than a rehabilitation model. From the development of prosthetics to the Braille language, technological advancements have always been presented as beneficial for people with disabilities while also becoming a new factor of exclusion or segregation. The current debate on disruptive technologies is no different from this historical dynamic.

This section is about the coming revolution – which seems inevitable – and the new legal framework required to regulate it. It will stand back from it to understand the standard account of what it means to be a human (human personhood) and mainly whether "cognition" or cognitive capacity defines what it means to be a person. It looks at how that "standard account" of what it means to be a human is no longer "standard," especially from the perspective of new science.

Rafael de Asis Roig examines the transhumanist approach to disability, focusing on its defining feature: human enhancement. The study of what underlies the philosophy of enhancement allows for connecting original humanism (lying at the foundations of modern human rights theory) with the transhumanist discourse. Both humanists and transhumanists, but particularly transhumanists, understand human nature in a way that discriminates against persons with disabilities. Diversity-based humanism comes in response to this, allowing us to address the role of emerging technologies vis-à-vis disability.

Bernadette McSherry deals with the ethical and legal aspects of neuroscience and neurointerventions. She argues that while neuroscience can aid in providing information about how the brain works, understanding how things can go wrong in brain function and how to address perceived impairments remain elusive. The article considers some of the ethical issues raised by the burgeoning industry of "neurointerventions," with a focus on brain-computer interfaces and brain stimulation and modification techniques. It argues that legal regulation may go some way toward alleviating ethical concerns about consent and autonomy. However, putting too much faith in neurointerventions as a cure for mental impairments ignores the importance of the social determinants associated with good and poor mental health and may serve to reinforce discrimination.

Francisco Bariffi explores the intersection between genetic engineering and disability. The article explores the basics of the genetic revolution, the crucial ethical implications, and the impact on the rights and dignity of persons with disabilities. He argues that recent breakthroughs opened up a world of new opportunities in the face of the CRISPR-Cas9 gene-editing method which allows high-precision cutting and editing of genetic information in the DNA of any living organism, including humans. The need for a new regulatory framework is evident. Existing human rights treaties – including biomedical treaties – do not give clear guidance. They were meant to prohibit and control certain things happening to humans but not to deal with humans becoming potentially superhumans or even nonhumans. The article concludes that any new policy conversation and the eventual regulatory regime must be based on the voices of those most directly concerned. Persons with disabilities are among the first to be directly concerned.

Piers Gooding deals with power, personhood, and data-driven technologies in the lives of disabled people, focusing on the rise of profiling technologies in mental health settings. The article focuses on the use of "digital phenotyping" or "behavioral" sensing in settings as diverse as hospitals, community-based services, homes, criminal legal settings, and direct-to-consumer products. It further explores the potential implications of biometric monitoring on individual dignity and personhood but expands the focus to collective concerns beyond an individualistic focus on the rights of data subjects. To reflect on these implications, the chapter brings together scholarship on algorithmic accountability, the Convention on the Rights of Persons with Disabilities, and Michel Foucault's "panopticism." The author concludes that governance would encompass the identification of harmful social consequences, as well as identifying benefits that may emerge and helping to adjudicate any societal trade-offs that may be required to achieve them.

Lastly, **Agustina Palacios and Iñaki Regueiro** address the intersection between gender and disability focusing on the exercise and enjoyment of sexual, reproductive, and nonreproductive rights. Based on the rights of autonomy and legal capacity, the article addresses the intersectionality between gender and disability. It includes a focus on both reproductive and nonreproductive rights, namely, the rights to have sex and to access to sexual assistance. An overview of the main barriers to the exercise of these rights is also present, including serious human rights violations, such as forced sterilizations. Finally, the authors propose three specific tools under the Convention on the Rights of Persons with Disabilities to prevent infringements of rights: accessibility, accommodations, and support.

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Transhumanism and Disability

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Rafael De Asís Roig

Contents

Abstract

This chapter examines the transhumanist approach to disability focusing on its defining feature: human enhancement. The study of what underlies the philosophy of enhancement allows to connect original humanism (lying at the foundations of modern human rights theory) with the transhumanist discourse. Both humanists and transhumanists, but particularly transhumanists, understand human nature in a way that discriminates against persons with disabilities. Diversity-based humanism comes in response to this, allowing to address the role of emerging technologies vis-à-vis disability.

Keywords

Transhumanism · Human enhancement · Human dignity · Human rights · Disability

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Introduction

Throughout history, categorizing humans as distinct beings has been a constant, and it has been part of modern humanism, which gave rise to the human rights rationale and the ideal of human dignity. Within this framework or discourse, such distinctiveness allows to consider human beings as unique. Note, however, that uniqueness here is not a synonym for singularity or specificity: when applied to human nature, uniqueness is tied to perfection.

Within this context, such distinctiveness and perfection arise from "the standard," i.e., a construct of "normal" traits allegedly shared by all human beings. This standard is represented by the body and the mind. Perfection thus results from the further development and enhancement of this standard through social constructs, giving rise to human excellence. As human beings depart from these perfect traits, they become less distinct, thereby moving further away from being considered human.

This approach to human nature has played a major role in ethics and law, and it ultimately pervaded the ties between the two, i.e., human rights along with a capacity-based or skills-oriented notion of human dignity. Within modern humanism's ideal of human dignity, there is an underlying concept of "person" that (i) entails having a set of abilities and (ii) gives rise to an inextricable relationship between "person" and "capacity" (De Asís 2004).

Capacity has always been a defining feature of moral agency or, better said, of the concept of "moral agent," construed as a being capable of acting with reference to right or wrong and engaging in moral discussion. Moral capacity means the ability to (i) make moral judgments and (ii) define and pursue life plans. Also, individuals have entered legal frameworks through the acknowledgment of capacity (Bariffi 2015). In order to hold rights and obligations, one must have been acknowledged legal capacity.

Capacity and ability also play a major role in individual rights. Human rights theory has been traditionally rooted in a model individual largely defined by (i) his or her rational "capacity;" (ii) his or her "ability" to feel; and (iii) his or her "ability" to communicate. This skill set is provided as the justification for human dignity and the acknowledgment of rights aimed at safeguarding the exercise of such dignity, i.e., the exercise of these abilities and capacities.

When building the notion of what is actually "human," the human rights theory embraced a contextual, situational, or environmental dimension. Barriers and their implications are also essential within this framework.

Therefore, human rights qualify as mechanisms designed to protect the exercise of human dignity by limiting, restricting, or removing any barriers hindering the aforesaid "abilities" or "capacities."

For a long time, only those meeting a (not always explicit) rationality standard could qualify as human rights holders, i.e., "able" persons or individuals with "capacity." Those failing to meet the rationality standard or having any cognitive disabilities (whether permanent or temporary) were not entitled to human rights, falling outside the scope of the human rights framework but still subject to it. Accordingly, their moral horizon depended on the “able” persons. As a result, the approach to persons with disabilities has relied on solidarity but has not necessarily been a matter of rights.

According to modern humanism, the ethical world is made up of dignified individuals or, better said, those who (abiding by a model of social life) are capable of reasoning, feeling, and communicating, orienting this skill set toward the achievement of their life plans while playing a specific and helpful role within society or their community. Anyone lacking these abilities can be entitled to rights, but these entitlements would not be justified on the basis of human dignity. The rights of the “non-able” would thus result from the decision of those “able,” who might consider them worthy of the said entitlements. Therefore, the approach to disability falls outside the scope of the rights framework – which caters to the “able.” Rather, disability is tied to benefits, assistance, and services.

This ethical, legal, and rights-based framework is fully in line with the so-called medical model of disability.

The medical model views disability as a scientific problem. Medical model advocates refer to disability as a health-related matter, i.e., an illness, so that persons with disabilities are defined by this condition. Therefore, they qualify as defective, faulty, sick, or abnormal persons.

Despite the designations (e.g., disabled or handicapped), the medical model provides a dignity-based definition of persons with disabilities. However, it is a passive form of dignity, where these persons are passive subjects and not active agents. Persons with disabilities are somehow granted dignity by able persons. Also, according to the medical model, persons with disabilities can contribute to society depending on how well they are rehabilitated.

Due to the close ties between disability and disease, disability policymaking is mostly health-related and assistance-based. The medical model aims at normalizing persons with disabilities, achieving their successful rehabilitation. Disability policies are thus subject to political discretion and resource availability. Therefore, in societies where the medical model prevails, fulfilling the rights of persons with disabilities largely depends on solidarity.

The medical model considers disability as a medical condition, portraying disability as a “personal tragedy,” defining disability in a fundamentally negative way. Consequently, this model gives rise to a negative outlook on disability in terms of diversity.

Until recently, these have been the main strands of the human rights discourse’s approach to disability. Nevertheless, there has been a shift in both the notion of disability and the human rights framework. A new form of humanism (humanism of diversity or diversity-based humanism) emerged in the late twentieth and early twenty-first century. It is a theoretical as well as legal and regulatory shift that has not yet permeated society.

Under this paradigm shift, the definition of disability does not only revolve around individual traits. In fact, disability becomes mostly defined on the basis of the barriers that might be encountered. According to this social model, disability does not have a scientific origin (Palacios 2008). Conversely, disability stems from social barriers, both physical and behavioral. From this perspective, the definition of persons with disabilities relies on condition (defects) and situation (barriers), but the model focuses on the contextual or situational dimension. In sum, under the social model, situation or context supersede any conditions or defects. Note that the social model of disability has placed disability within the human rights framework.

Persons with disabilities are as dignified as anyone else, but such dignity must be construed as an active dignity, meaning that persons with disabilities are the ones shaping the consequences of this acknowledgment regarding their life plans.

Disability-related policies cease to be assistance-based. The spotlight is no longer on benefits and assistance, which are superseded by rights and entitlements. Under the social model, the claims of persons with disabilities are legally secured and no longer depend on political discretion and resource availability.

Although the social model focuses on barriers to define disability, it does not dismiss the role of condition and thus the role of diversity. According to the social model, disability also expresses the richness of human diversity.

Furthermore, the human rights discourse has modified the notion of dignity and the equality narrative, detaching (to some extent) the ties between capacity and dignity. The human rights discourse has contextualized dignity, opening to potential and departing from the talent or skills-oriented narrative. A dignified human life, combining autonomy and dependency as core human dimensions, has become the essence of dignity.

At the inception of individual rights, inherent equality was a defining feature shared by all human beings and thus a guiding principle. However, the current rights discourse regarding equality is difference-based. We are different from each other, and we are in different situations. Therefore, equality and non-discrimination revolve around two main dimensions: negative and positive difference. Negative difference entails finding the aspects making us different that are irrelevant to justify unequal treatment. Positive difference entails finding the aspects setting us apart that provide grounds for a different treatment.

From this approach, treating someone differently would qualify as discriminatory if there are no grounds for such difference or if, there being any potential grounds or justifications, these are superseded by overriding arguments or interests. Consequently, discrimination occurs (i) when meaningless differences are taken into account to provide a prejudicial treatment (whether directly or indirectly) and (ii) if meaningful or relevant differences are overlooked to provide a beneficial treatment (whether directly or indirectly). The relevance of differences and reasonability of arguments have become core aspects when discussing equality within the human rights framework.

As noted above, this new humanist discourse can be found in both human rights theory and human rights law, but not within society.

However, a philosophical movement seems to be emerging to challenge these premises. This movement does not only rely on the medical model, but also reminds us of a previous approach to disability: the disregarding model. This discourse's starting point is the aforesaid perfect "standard," seeking to improve it through technology. Watch out for transhumanism.

On Transhumanism

Transhumanists seek to enhance the human condition physically, intellectually, emotionally, and morally relying on science and biotechnology (Ferry, 2017). The proponents of this philosophical movement advocate the use of technology to improve persons' lives and to enhance longevity, mood, and cognitive abilities.

For transhumanism, the end of mankind is inevitable if the developments of science and technology are not embraced, obtaining instruments and apparatus that allow fighting against this outcome. This development shall create unlimited unique machines that could merge with humans.

Transhumanists defend human beings' freedom to use technology in order to enhance their lives and the lives of others, to be stronger, to live longer, to be less violent, etc. Transhumanist thinkers firmly believe that (i) technology can solve contemporary social problems (Llano, 2018); (ii) human enhancement technologies should be widely disseminated; (iii) individuals should be free to choose from these technologies; and (iv) parents should have complete authority over which enhancements – if any – they apply to their children.

The *Transhumanist Manifesto* was published in 1983, and the *Transhumanist Declaration* was drafted in 1998. The *Transhumanist Declaration* was signed by the most prominent transhumanists, it has been amended several times, and it lays down the guiding principles of transhumanism. Some of these principles and premises stem from humanist thinking.

The *Transhumanist Declaration* is worded as follows: "Policy making ought to be guided by responsible and inclusive moral vision, taking seriously both opportunities and risks, respecting autonomy and individual rights, and showing solidarity with and concern for the interests and dignity of all people around the globe. We must also consider our moral responsibilities towards generations that will exist in the future." The *Transhumanist Declaration* also refers to technology-related risks: "Research effort needs to be invested into understanding these prospects. We need to carefully deliberate how best to reduce risks and expedite beneficial applications. We also need forums where people can constructively discuss what should be done, and a social order where responsible decisions can be implemented."

One of the first works on transhumanism (More 1990) defines it as the successor of humanism although going beyond humanism by peering into the future in order to better understand our possibilities. Transhumanists argue that human nature is not an end in itself, nor should we abide by it. Technology will turn us into posthumans, thereby creating a new species (Harari 2017).

Other transhumanist claims, however, seem to depart from humanist thinking: "We favour allowing individuals wide personal choice over how they enable their lives. This includes use of techniques that may be developed to assist memory, concentration, and mental energy; life extension therapies; reproductive choice technologies; cryonics procedures; and many other possible human modification and enhancement technologies" (*Transhumanist Declaration*).

Transhumanism advocates the need for achieving a concept of human dignity that could be extended to posthuman beings (Bostrom 2005a). Transhumanists claim that we can legitimately reform ourselves and our natures in accordance with *humane* values and personal aspirations.

In any event, it is worth differentiating between three versions of transhumanism (Diéguez 2017). First, there is cultural transhumanism, based on postmodern theories. Cultural transhumanism challenges premises such as the boundaries of nature, the potential of human enhancement or the concept of human dignity. Second, there is biological transhumanism, supporting biological enhancement, improving cognitive abilities (biological uplift), enhancing longevity, and replacing natural randomness by selection and artificial genetic design. Third, cybernetic transhumanism intends to create a new species by merging human and machine.

Transhumanism rejects the view of nature as something constant and unchanging and argues that the moral value of human beings does not exist because they belong to a species but because of what humans do. Therefore, technological advances should be used for the moral improvement of humankind. This improvement will not produce negative effects, since it aims to enhance the moral behaviour of people, so it could hardly be considered as a moral evil (Persson 2012).

Nick Bostrom, a prominent transhumanist, relies on “The Fable of the Dragon-Tyrant” (Bostrom 2005b) to justify the use of technology for human enhancement with the aim of “killing death.” In this tale, ten thousand human bodies had to be delivered every evening to the foot of the mountain where the dragon-tyrant lived. Some would be devoured upon arrival, and others would be locked up in the mountain before eventually being devoured. Unable to beat the dragon, humans simply obeyed its commands, and they even set up a social structure abiding by the dragon’s needs. However, a group of eminent engineers began to think that they could beat the dragon, and they came up with the way to do it. After a struggle with priests, bureaucrats, dragonologists, etc., the engineers killed the dragon once and for all.

The dragon embodies death, and its victims represent the ill and dying human beings. The fable provides three stances against the dragon: (i) resignation, surrender, or graceful accommodation; (ii) cooperation; and (iii) fighting evil. Transhumanism represents this third stance.

If limited to the enhancement of human life, the purpose of transhumanism could be acceptable. But even in this simple wording, it raises concerns, since the concept of enhancement (or improvement) remains unclear. In addition, the notion of enhancement needs a starting point, the subject of enhancement, i.e., what needs improvement, whose value steadily diminishes as the enhancement is performed and the starting point is pushed away from the status to be achieved. There is no doubt that this has implications for persons with disabilities.

Aside from the most radical transhumanist stances – expressly claiming that persons with disabilities are not as morally worthy as “able” persons – the substance of transhumanism is that of the medical model: disability is an illness or disorder that can be cured through technology. This claim even overlaps with disregarding model claims (Fletcher 2014): (i) disability causes suffering, thereby rendering meaningless the lives of the disabled; and (ii) curing disability (if possible) is not worth the costs or social changes required.

The disregarding model advocates dismissing or disregarding persons with disabilities or, at best, socially excluding them. Under the disregarding model, persons with disabilities are defined on the basis of their condition. They have various defects, and thus they fall outside the standard giving rise to human dignity. As a result, they are not granted human dignity.

Public authorities have no obligations whatsoever toward persons with disabilities, so public policymaking need not address disability. If there were public policies in the field of disability, they would be intended to protect society from the (financial or moral) damage caused by persons with disabilities. Accordingly, disregarding model advocates consider that it makes no sense to deal with non-discrimination regarding persons with disabilities, since their disabilities are regarded as a source of suffering, both for the disabled and for society as a whole.

Although the disregarding model can be traced back to the classical world, some of its models remain in place, upheld by some twentieth-century tragic experiences (like Nazi Germany). Even now, in the twenty-first century, we can feel its presence.

The COVID-19 pandemic has evidenced that the disregarding model is out there, still present, and that it can openly and boldly project itself beyond disability, affecting the elderly. In fact, this approach to disability might have never disappeared. The notion of human dignity stems from an ability-based or skills-oriented human model that relies on individuals' contribution to society. The clearest expression of the disregarding model is the social utility or social worth criterion, stated in many associations' and national and international committees' documents when setting the priorities to allocate health-related resources.

Regarding transhumanism and its impact on disability, it is worth mentioning a transhumanist claim shared by other schools of thought. The claim refers to the effort and cost of building a society where persons with disabilities had equal opportunities as anyone else (Buchanan, Brock, Daniels and Wikler 2000).

Limiting a right on the basis of its excessive costs is an argument for which there is no room in the context of rights, unless it is proven that the mentioned cost is unbearably harmful for other rights. At this point what is really relevant is not the cost itself, but the impact on the right. Economy is a tool which, as such, shall be at the service of rights and not the other way around.

A given right can be restricted based on its cost only if such cost entails nonfulfillment of other rights at stake. The use of an argument based on an unreasonable cost shall be examined with great care, and it shall be even deemed as lacking proper justification when this cost does not entail a real and blatant nonfulfillment of third parties' human rights. In other words, there is no room for an argument that takes into account the cost with no regard to the context of rights. Its use, as an admissible argument when it comes to rights, requires to be tied to these (in terms of expressing a limitation set on the rights of others).

On Cyborgs and Enhancements

Keep in mind that improving living conditions is not a solely transhumanist ideal. It is shared by almost all philosophical movements. Mankind has always been concerned with human enhancement, including salient humanist thinkers like Pico della Mirandola, Bacon, Rousseau, Condorcet, Kant, Ortega y Gasset, or Hannah Arendt.

Human enhancement can also be found within the persons with disabilities' discourse, regarding both situation and condition, alongside the notions of support, assistance, and the fight against barriers. The struggle against disability-based discrimination has given rise to a support system founded on both material and human resources. Material resources include basic tools, such as walking sticks, as well as more sophisticated devices, e.g., wheelchairs, bionic arms, or chips. Indeed, the concept of "cyborg," commonly used in transhumanist scholarly works, is not foreign to disability.

Currently, there are some really famous cyborgs. Neil Harbisson is best known for having an antenna fixed to his skull to "hear" colors. Moon Ribas wears seismic sensors in her feet. Chris Dancy has 11 sensors implanted throughout his body monitoring his vital signs 24 hours a day. In 2002, Kevin Warwick (scientific, engineer and college professor) implanted a device into his arm connecting his nervous system to the Internet, allowing him to control an electric wheelchair and an intelligent artificial hand. In 2016, Switzerland held the First Cyborg Olympics (the event was officially called *Cybathlon*), where cyborg athletes with bionic implants across the world competed against each other.

However, let us stop here for a moment: are these news related in any way to the world of disability? The answer will depend on our understanding of the concept of "cyborg" and "disability."

We have already discussed the meaning of "persons with disabilities" and the existing models or approaches thereto. The concept of "cyborg" was coined by Manfred E. Clynes (Austrian scientist and musician) and Nathan S. Kline (US scientist) referring to an enhanced human being. Cyborg comes from "*cyb*ernetic *org*anism," meaning a human being with an electronic device permanently implanted in his or her body.

Nevertheless, not everybody construes "cyborg" in the same way. Some argue that the device need not be electronic. Others claim that there are temporary cyborgs (human beings with devices temporarily implanted or fixed to their body parts).

Cyborgs are nothing new. Yet again, the history of cyborgs depends on our understanding of this notion. If cyborgs are necessarily tied to electronic devices, their history begins with science fiction literature in the late nineteenth century and, mostly, over the twentieth century. However, if cyborgs do not need to have electronic devices to qualify as such, the concept of cyborg could be traced back to the year 1550 B.C. and ancient Egyptian prosthetics.

Prosthetics brings us closer to the disability framework. In fact, a broad notion of cyborg could encompass the merge of a human being and his or her wheelchair or, even with any technological assistance, aid or support (in 2014, the US Supreme Court ruled that cell phones were part of the human anatomy in *Riley v. California*). Yet again, there are some outstanding examples in the media.

In 2014, 10 years after he was paralyzed due to a car accident, Nathan Copeland (at 28 years old) became the first human being to recover a "natural" sense of touch using a mind-controlled robotic arm. Les Baugh is a double amputee who lost both arms in the 1970s and now has two mind-controlled robotic arms. Hugh Herr, a biophysics professor, has two bionic limbs; he is best known for his achievements in biomechanical engineering and for being BionX's founder (according to the corporate website, a company focused on improving human imperfection).

In a nutshell, "cyborg" refers to the merge of human and technology, thus covering both persons with and without disabilities – as the anthropologist Amber Case points out: "We are all cyborgs now."

In any event, cyborgs are controversial. We probably deem some of the previous examples acceptable without further concerns, whereas some others could be objectionable. We tend to consider acceptable or unobjectionable that the enhancements be aimed at correcting social disadvantages.

It is a well-known issue for bioethics: the clash between therapy and enhancement (i.e., between therapeutical and enhancement treatment) or between curative medicine and perfective or augmentative medicine. This clash has major implications, since it allows to draw the boundary between what is considered admissible and what is not. In November 2018, He Jiankui, a Chinese scientist, was all over the news worldwide after claiming to have created two genetically edited babies. More specifically, he had modified the gene called CCR5, used by HIV as the gateway to attack our immune system. As criticism mounted, He Jiankui responded that he had performed a therapeutic intervention.

The boundary between enhancement and therapy is blurry. What some call enhancement is most certainly considered therapy by others. A medical product for children's ADHD (therapy) can also be used to perform better on a test (enhancement). Treatments that are objectionable at first end up being accepted if applied to persons with disabilities. For instance, we are fine with giving growth hormones to short people, but giving them to tall persons would be frowned upon. We agree that individuals with depression should take antidepressants, but otherwise we are not fine with the use of antidepressant drugs.

Enhancements raise concerns, which become more serious if persons with disabilities are involved. As noted above, the distinction between enhancement and therapy is unclear, but the first problem is that we do not know if there is such a thing as "objective enhancements."

Some claim that enhancing longevity (Singer 2002) or trying to lead the best life (Savulescu 2002) are objective enhancements. It is not a stretch to question that longevity or leading the best life are absolute or objectively good, arguing that the very notion of enhancement is subjective by definition and that it can vary depending on context and culture.

Let us think of former NBA player Yao Ming. He was 2.29 meters tall (7′6″), which clearly gave him a competitive advantage for professional basketball, thus allowing him to make a lot of money. Nonetheless, there is no doubt that this is a matter of context. Being that tall can help you, but it can also be a problem. See, for example, the so-called *Club de los altos y altas en Chile* (a Chilean institution were tall men and women share their problems).

In the field of disability, in 2002, Sharon Duchesneau and Candace McCullough announced their decision to have a child via artificial insemination; so far, so good.

But they were both deaf, and they decided that their children should be too. As is well-known, members of the deaf community consider themselves a cultural minority defined by their use of sign language. In fact, members of the deaf community define themselves as persons using sign language to communicate.

Even admitting that there are "objective enhancements," these can be discriminatory and unreasonable (Lema 2015). Nicholas Agar discusses parents' ability to alter their children's skin color through genetic engineering (Agar 2004). They can either (i) darken the children's skin, to mitigate ozone layer depletion effects, or (ii) lighten the skin, in order to prevent racial discrimination in a racist society. Agar supports the first option, but rejects the latter on grounds of discrimination, adding that it is not admissible to make a person's worth depend on his or her skin color.

There are similar examples in the field of disability. Imagine that losing our lower limb puts us in a wheelchair forcing us to face numerous barriers, but we can get a prosthetic leg choosing between two options. On the one hand, we can pick a prosthetic limb that works exactly as our missing leg but without a leg's appearance. On the other, we can choose a less functional prosthetic limb that looks exactly like a leg. Some would not hesitate to pick the first option based on its functionality, but others might consider that such strange looking limb would stigmatize the person using it and therefore would pick the second option. The latter choice evidences empathy and understanding toward the discriminatory treatment suffered by many persons with disabilities.

Overlooking this potential discrimination regarding human enhancements could lead us to accept discriminatory and exclusionary decisions affecting life choices and persons. Savulescu is in favor of leading the best life, i.e., maximizing well-being. He put forward the "Principle of Procreative Beneficence," according to which parents should pick among the possible children those who are expected to have the best life. Otherwise, they are immoral parents (Savulescu 2002).

Admittedly, many enhancements are performed on oneself, so that they only involve an individual deciding on his or her own body exercising individual autonomy. However, this neither makes this issue less complex nor excludes the possibility of discrimination.

Self-evidently, one of the largest ethical concerns regarding these enhancement technologies relates to securing equal opportunity and, therefore, to the possibility of widening the gap between rich and poor. There is no doubt that this gap particularly affects persons with disabilities.

Lee Silver aptly examined this issue. He predicts a future defined by the appearance of reprogenetics (i.e., the fusion of reproductive technologies and genetics), where prospective parents can choose which genes their children would receive (Silver 2007). Over time, society segregates into "Naturals" and "GenRich." In Silver's world, it is not a stretch to imagine that vulnerable persons would be "Naturals" (i.e., the underprivileged class) and that their rights would hardly be fulfilled.

We could also flip the argument and use technology to ensure equality. Technology is often portrayed as an instrument to end disabilities. Emerging technologies fuel this line of reasoning by disregarding persons with disabilities' actual well-being and experiences.

Aside from scholarly works, this is, surprisingly, the most widely spread approach to the use of technology in the field of disability. Technology is seen as an opportunity, as the chance of persons with disabilities to level the playing field. Certain technology supporters somehow rely on this idea. In fact, there are claims that a society of enhanced human beings would provide greater chances for redistribution. Still, this use of technology could be discriminatory for persons with disabilities in terms of stigmatization and devaluation.

Condition, Situation, Enhancements, and Human Rights

Considering the definition of persons with disabilities and its two axes, condition and situation, we notice how the discussion on human enhancement focuses more on the conditional side than on situational aspects. Most likely, this is why the persons with disabilities' movement, for its most part, reject these approaches (Romañach 2009) and rightly so, as discussed below.

Keep in mind that persons with disabilities also have a conditional dimension, i.e., they are also condition, not only situation, and they do not only face environmental and social barriers. Thus, the application of emerging technologies to disability should not be dismissed outright. In fact, some argue that using technology for human enhancement interventions is a moral imperative.

The enhancement discourse does not take into account that human life has always been a struggle against the limits of nature and social conventions (Nussbaum 2002) and that "(...) freedom consists in a persisting negotiation with the given" (Sandel 2007). Some enhancements threaten the moral development of personality. Many thinkers claim that moral development entails significant efforts and sacrifices that can disappear as a result of technological enhancement. These technologies have the ability of considerably lessening our autonomy and accountability and thus our own moral agency. J. Habermas draws upon the notion of human dignity, i.e., what actually allows us to recognize one another as members of the same species, claiming that there is no justification for any intervention that could alter such recognition (Habermas 2003).

At this point, however, we can hardly (i) determine the features and traits identifying human beings and making us distinct and therefore (ii) claim that those features and traits remain in place throughout the history of mankind. During our lives, we might suffer radical changes that can impact our personal identity. But these changes do not call into question that we remain part of the human species. So, why would artificial enhancements have this ability? Why would they allow to challenge our human nature?

Within this context, we often speak of "normalcy" or rely on standards. Accordingly, some argue that the limit for human enhancement is the standard, i.e., enhancements cannot provide humans with attributes or abilities that go beyond what is normal. But this is, indeed, one of the issues regarding the notion of enhancement: that the starting point be a standard that is blurred and arguably has any moral value. Moreover, “normalcy” or “the standard” are conflictive ideas in the field of disability.

When we seek the best for our loved ones, we often try to drastically alter environmental factors (we try that our children develop skills and our interventions relate to what they eat, their training, sports, etc.), but yet we question interventions related to other aspects (e.g., genetics). This also applies to prosthetic limbs and other devices used to improve or correct any defects. If we define human nature relying on both the conditional and situational axes, we should accept any conditional interventions just like we admit interventions to improve situational aspects (mostly those related to environmental factors).

Despite this, enhancements pose several challenges when applied to persons with disabilities. Within this context, enhancement advocates tend to consider persons with disabilities as ill, where the enhancements qualify as a therapeutic treatment from the medical model’s perspective (Hall 2020). Persons with disabilities are underestimated to the point where some argue that their lives are meaningless. Many of these claims are based on a model human being or standard that can exclude others and be the basis for discrimination. This standard is tied to perfection. It conveys the idea that as we move apart from it, life has a lesser meaning or happiness becomes harder to achieve. From this perspective, disability is portrayed as a source of imperfection or suffering and, at best, as a natural disadvantage to be removed.

Assuming that conditional diversity is an issue to be eliminated, enhancement technology promises to end it, disregarding what is most discriminatory toward persons with disabilities: situation. There is a quote from Rousseau’s *Emile, or On Education* that perfectly summarizes this: “What madness for a fleeting being like man always to look far into a future which comes so rarely and to neglect the present of which he is sure!” (Rousseau 2011).

We should prioritize overcoming barriers over fighting these so-called defects. Let us recall the parents from Agar’s example. They should be entitled to choose their children’s skin color to protect them from ozone layer depletion effects, but only for this reason, since lightening their skin to avoid discrimination in a racist society would be unacceptable and would make no sense. The point being that, aside from the parents’ choice – either darkening or lightening their children’s skin – the appropriate strategy from a human rights approach would be to (i) prevent ozone depletion and (ii) eradicate racism. The above example where a person needed a prosthetic leg to avoid the barriers attached to being in a wheelchair elicits the following question: why are we not implementing a strategy aimed at removing barriers altogether? Regarding technology, this could translate into prioritizing accessibility policies.

Assuming a rights-based approach, removing barriers should prevail over (i) trying to eliminate defects and (ii) human enhancement programs. Enhancement technology advocates should be aware that persons with disabilities do not “suffer” disability, but rather *suffer from* discrimination. The whole human enhancement framework must involve social and political action, not genetic and biological interventions (Hall 2016).

Original humanism, which remains in place, and transhumanism share this negative outlook on disability, as a conditional deficiency stemming from human nature. Both original humanists and transhumanists agree on human beings' distinctiveness, and they believe that disability exemplifies human imperfection. Both humanist and transhumanist discourses rely on "normalcy" or "the standard" (embodied in model persons and model societies) as a central reference.

Humanism was founded on a consideration of human nature that became increasingly more distinct as it reached higher degrees of excellence, resulting from social constructs. In a way, the ultimate expression of human dignity occurs when these degrees of excellence are achieved. Transhumanism simply takes another step with respect to humanism (despite some transhumanists' strong criticism of enlightened humanism). The transhumanist starting point is what humanists considered the "excellent" human being, which is now deemed imperfect (just like original humanists found that persons with disabilities were defective), thus seeking to enhance it (striving for human excellence) through technology. The expression of dignity occurs when these excellence levels are reached.

For humanists, human excellence was the aim (based on an ability-based or skills-oriented human model), whereas according to transhumanists, such ideal of human excellence is the starting point. This is why humanists considered disabilities as conditional defects to be cured and transhumanists deem them unacceptable. According to the humanist discourse, disabilities simply show human imperfection. Transhumanists agree, although apparently adding that the lives of the "disabled" are meaningless.

Looking at it from the disability models, humanists' approach to disability is based on the medical model. In contrast, transhumanists regard disability from the disregarding model.

As discussed above, we claim that humanism and transhumanism are closely connected. This might seem an overstatement. Nevertheless, if we examine children's education (which constitutes a defining aspect of philosophical movements), both humanists and transhumanists clearly consider and describe disability as a conditional defect or deficiency, although this consideration is even more intense within the transhumanist discourse (Alexandre 2017).

Therefore, we must support the so-called humanism of diversity or diversity-based humanism. It is in line with the social model, and it emerged with the UN Convention on the Rights of Persons with Disabilities.

Diversity-based humanism is not at odds with technology. Enhancements raise greater concerns if justified on the basis of (i) a discriminatory and stigmatizing model human being or (ii) a discriminating social structure lacking equal opportunities. The very word "enhancement" contributes to all this. Therefore, in order to neutralize the concerns reasonably raised from the disability framework, we must implement a change in society, normalizing it by eliminating discrimination against persons with disabilities. Accordingly, enhancements will not fall within a specific approach to persons with disabilities, but within the general framework under which the freedom to get enhancements is justified if they (i) are available to everyone; (ii) do not affect individual rights of human beings; and (iii) do not undermine diversity (which is both a reality and an essential asset that cannot be waived or left aside).

In this vein, technological development cannot favor a social structure undervaluing disabilities. If technological development is aimed at remedying personal defects overlooking social shortcomings (environment, habits, behaviors, contexts, etc.), such technological development is most certainly in conflict with human rights.

The ethical framework governing the rights theory in this field must be critical regarding the idea of human dignity in the manner it has been created and specified from modernity and Enlightenment. An idea of human dignity based on a conception of human beings and society that, in a certain sense, is also present at the origin of the search for machines and devices that achieve perfection. The human model of the Enlightenment was supported by some patterns based on perfection and a social model that, at times, imposed an exclusive lifestyle. Human dignity has been built highlighting what we might conceive as an abstract dimension of the person, leaving aside the contextual or location dimension. It has been built based on patterns of "normalcy" that historically have coincided with those of the powerful (Barranco 2011). Thus, we must eliminate certain ideal models we project on the concept of human dignity that make the situation in which some people are found unworthy and different (Cuenca Gómez 2015). Equally, we must value human diversity and consider it as one of the great wealth of our societies.

Human rights provide the ethical, legal, and political framework for contemporary societies. They are the guiding principles that should govern technological development. This human rights discourse gives rise to three general guiding statements applicable to emerging technologies from a rights-based approach: (i) scientific and technological advancements should serve humanity's well-being, sustainable development, world peace, and the protection and conservation of biodiversity; (ii) human interests and well-being prevail over society's or science's exclusive purposes, including respect for human dignity and human rights protection (e.g., the rights to life and moral integrity, privacy, free will or self-determination); and (iii) securing human dignity entails protecting human diversity, the environment, the biosphere, and biodiversity (including a sustainable use of resources and a fair allocation of the profit) (De Asís 2015).

The basis for diversity-based humanism governed by human rights must be H. Jonas' categorical imperative: "Act in such a manner that the effects of your actions are compatible with the permanence of genuine human life on Earth" (Jonas 1995). Diversity-based humanism should also be open to technological and scientific progress, which requires not fully dismissing transhumanism.

Transhumanists (i) disregard very significant matters regarding human enhancement and (ii) overestimate what can be accomplished through technological innovation. Therefore, their arguments are not convincing. However, there is nothing intrinsically wrong with trying that future generations' lives be longer and more fulfilling in terms of talent and accomplishments (Dworkin 2000).

It is for human beings and human beings only to categorize human nature, i.e., to define what should be considered "human," and must be done within an ethical, pluralistic, diversity-friendly, and nature-oriented framework. This categorization of human nature should take into account several circumstances, aspects, and traits making up our identity, such as death, dependency, pain, suffering, effort, imperfection, or limitations, which are often the clearest expression of human diversity and freedom.

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Neuroscience and “Neurointerventions”: Ethical and Legal Issues

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Bernadette McSherry

Contents

Abstract

“Neuroscience” is the modern term for the study of the brain and the nervous system, but attempting to explain what the brain does has occupied scholars for centuries. While neuroscience can aid in providing information about how the brain works, understanding how things can go wrong in brain function and how to address perceived impairments remain elusive. This chapter considers some of the ethical issues raised by the burgeoning industry of “neurointerventions,” with a focus on brain-computer interfaces and brain stimulation and modification techniques. It argues that legal regulation may go some way toward alleviating ethical concerns about consent and autonomy. However, putting too much faith in neurointerventions as a cure for mental impairments ignores the importance of the

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social determinants associated with good and poor mental health and may serve to reinforce discrimination.

Keywords

Neuroscience · Neurointerventions · Brain-computer interfaces · Psychosurgery · Ethics · Consent · Autonomy

Introduction

The brain is the most complex organ in the human body, both in structure and function. "Neuroscience" is a broad term used to describe the study of the brain and the nervous system, and substantial amounts of data have been and continue to be collected by neuroscientists to help understand what brains do. At the same time, new devices and technology are being developed to describe, stimulate, and manipulate brain activity.

In November 2019, for example, Elon Musk was reported as stating that the work of his neural-technology company, Neuralink, which is developing brain-computer interfaces, could "solve a lot of brain-related diseases" such as "autism, schizophrenia, memory loss" (Asher Hamilton, 2019). While issue could be taken with all these examples being considered "brain-related diseases," the idea that many "disorders" are, in the words of Thomas Insel (2013), "biological disorders involving brain circuits" is driving neuroscientific endeavors to understand and rectify perceived impairments.

This chapter considers some of the ethical and legal issues raised by the burgeoning industry of "neurointerventions," with a focus on brain-computer interfaces and brain stimulation and modification techniques.

The next section provides an overview of historical explanations of the brain as the source of certain impairments and how the development of a range of neurointerventions is part of an historical continuum. The chapter then examines the ethical issues associated with how best to conceptualize the continuing search for how to perfect the brain, before providing an overview of how the law has been and could be used to regulate the use of neurointerventions. The final section provides an overview of the drawbacks to focusing on neuroscience and neurointerventions to address perceived impairments.

The Allure of Neuroscience

Sabrina Ali et al. (2014: 1) refer to the "allure of neuroscience" and use the term "neuroenchantment" to describe the "sub-judicious fascination with brain science." This may in part explain the current focus on devices and technological interventions designed to enhance brain function as well as intracerebral manipulation to alleviate the symptoms of "biological disorders involving brain circuits" (Insel, 2013).

The US BRAIN Initiative, the European Union's Human Brain Project, and the Australian Brain Alliance are among some of the global initiatives that have invested more than US$7 billion into neuroscientific research (Carter, Walvisch & Haylock, 2019: 2).

However, the search for explanations of brain function, including in relation to consciousness, is nothing new. Neuroscience may be the modern term for the study of the brain and the nervous system but attempting to explain what the brain does has occupied scholars for centuries.

It is beyond the scope of this chapter to traverse the terrain of theories of mind. Suffice to say, it is doubtful whether there can ever be a single theory of brain function because the human brain is such an integrated, evolved structure. As Anne Churchland and Larry Abbott (2016: 349) point out:

> Given the range of phenomena studied in neuroscience, demanding unity of viewpoint, methodology or depth of understanding, even in a single system, seems both unrealistic and counterproductive.

In addition, Allen J Frances and Thomas Widiger (2012) argue that neuroscience can aid in providing information about how the "normal" brain works, but understanding how things can go wrong in brain function remains elusive.

The history of brain modification and stimulation techniques – from surgery to implanting technological devices into the brain – indicates that in relation to treating (perceived) brain disorders, neurointerventions are nothing new. The following provides a brief overview of some of these techniques.

Brain Surgery

There is some evidence that trepanation or trephining, whereby a hole is surgically made into a skull, occurred in prehistoric times (O'Callaghan & Carroll, 1982: 1). The anatomist Paul Broca (1867), for example, detailed an instance of this procedure having been performed on the head of a living human after analyzing a prehistoric skull found in the Cuzco district of Peru. Why trepanation occurred is subject to debate. Mark O'Callaghan and Douglas Carroll (1982: 4) suggest, however, that one rationale was to relieve the symptoms of perceived mental impairments. (The term "mental impairments" rather than other terminology is used throughout this chapter in line with its use in Article 1 of the United Nations *Convention on the Rights of Persons with Disabilities*).

O'Callaghan and Carroll (1982:4) point to a section in a twelfth century manuscript, which was possibly written by Ruggerio Frugardi of Palermo, that refers to the skull being perforated to allow matter to escape as a remedy for "mania and melancholy."

While neurosurgery to treat brain injuries such as skull fractures or to treat headaches, epilepsy, or neurological disorders such as Parkinson's disease has become an accepted part of medical practice, "psychosurgery" to treat mental impairments has been fraught with controversy.

In 1891, Gottlieb Burckhardt published an account of his experiments with "cortical extirpation," the severing of connections between certain brain areas, to treat his patients diagnosed with incurable psychoses who resided at a Swiss institution for the insane. O'Callaghan and Carroll (1982: 4–5) point out this was probably the first modern account of psychosurgery, but it took some time before these experiments were replicated given that while one patient's symptoms were relieved, one patient died and another developed epilepsy after the operation.

The Portuguese neurologist Egas Moniz (1935) wrote about a technique termed a prefrontal leucotomy as a method of treating severe mental impairments. This technique involved making incisions along the junction between white and gray matter that destroyed connections between the prefrontal region and its connections with the limbic system. Walter Freeman and James Watts (1947) subsequently developed a standardized method which became known as a lobotomy. James Caruso and Jason Sheehan (2017) detail the subsequent falling out between Freeman and Watts about surgical techniques and how poor outcomes for patients along with various social factors led to the decline of surgery that destroyed brain tissue to modulate neural function.

Electroconvulsive Therapy

During the 1930s, the Italian neurologist Ugo Cerletti and his assistant Lucio Bini began inducing seizures in animals by the administration of electrical stimulus via electrodes applied to parts of the head. In 1938, they used electroconvulsive therapy (ECT) for the first time on a person experiencing delusions (Cerletti & Bini, 1938). Clinicians subsequently found that ECT was associated with beneficial results for people diagnosed with severe depression (Metastasio & Dodwell, 2013).

Early ECT practice involved administration without muscle relaxants and anesthesia, leading in some instances to severe physical injuries because of full-scale convulsions. The use of ECT has been associated with memory loss (Fraser et al., 2008), but electrode placement and parameters can now be modified to decrease this likelihood.

How ECT works is yet to be determined. Changes to brain function appear to evolve over time which is why it is generally administered two or three times a week over several weeks. As with psychosurgery, the use of ECT has proved to be controversial, and its use is generally regulated through legislation (McSherry 2019).

Transcranial Magnetic Stimulation

Transcranial magnetic stimulation (TMS) is a noninvasive technique that involves creating a powerful electrical current via an electromagnetic coil resting on the scalp (Trimble & George, 2010: 320ff). The current creates a strong but brief magnetic field that can pass through the skull and soft tissue. This current can be pulsed in a way that stimulates neural activity in regions near the surface of the brain. Similarly, transcranial direct current stimulation (tDCS) involves running a low-level electric current through regions of the brain by placing pairs of electrodes on the scalp to change neural activity in the brain region underneath.

In the early 1900s, psychiatrists Adrian Pollacsek and Berthold Beer patented an electromagnetic device as a treatment for depression and neuroses (Beer, 1902), but it wasn't until the mid-1980s that experimentation with TMS became a focus for clinical research (Barker et al., 1985). In 1995, an American psychiatrist, Mark S George, and colleagues began experimenting with repetitive TMS as a treatment for depression (George et al., 1995). After several subsequent studies, the US Food and Drug Administration (FDA) agency approved repetitive TMS as a treatment for depression (Trimble & George, 2010: 323).

There is some research suggesting that repetitive TMS "transiently disrupt [s] neuronal activity for periods exceeding stimulation duration" (Horvath et al., 2011: 137). As with ECT, it is unclear how TMS works and which specific prefrontal or other brain location should be targeted by it.

Deep Brain Stimulation

The use of intracerebral electrodes to stimulate the brain (commonly referred to a deep brain stimulation) may be used to probe or modulate activity in neural circuits (Lozano & Lipsman, 2013). The electrodes are implanted unilaterally or bilaterally deep inside the brain and electrical currents are delivered from a pulse generator implanted in the abdomen or under the collarbone through leads into the electrodes.

While DBS was first approved in the 1990s as a treatment for tremors associated with Parkinson's disease, more recently it has been used to alleviate symptoms of severe depression (Holtzheimer & Mayberg, 2011) and obsessive-compulsive disorder (Figee et al., 2013).

Because DBS is invasive, it has more risks associated with it than TMS. On the other hand, it has fewer risks than ablative neurosurgery which is irreversible (Glannon, 2009). The stimulator for DBS can always be turned off and the implanted electrodes removed.

Walter Glannon (2009: 290) provides an overview of studies that have indicated significant risks with DBS being used to treat "psychiatric disorders," including inducing hypomania which was resolved after adjustment of the stimulator. He argues (2009: 290) that because any adverse effects are "not predictable from one patient to the next," extra care must be taken with weighing up potential beneficial and harmful effects.

Implantable Brain-Computer Interfaces

The rationale for brain-computer interfaces (BCI) has focused on enabling people with extensive paralysis or brain injury to control a limited range of motor functions. BCI involve direct connections between the brain and a computer, with bidirectional feedback between the user and the computer producing physical changes in the brain that can restore a degree of motion control (Hochberg & Cochrane, 2013). The feedback can allow the person to translate intentions into physical actions.

For example, a team led by researchers at the University of Melbourne has developed a device called a Stentrode which can be inserted into a vein that sits just under the skull and which transmits brain signals to a computer which then translates them into onscreen command (Oxley et al., 2020).

Elon Musk and his company Neuralink appear to be working toward increasing the number of electrode threads in their implantable device. In one published white paper (2019), they report building ultra-fine polymer probes, a neurosurgical robot, and custom high-density electronics and experimentation with inserting the flexible electrode threads into rats at a rate of six threads per minute. They refer to the aim of using such technology for individuals with spinal cord injury to operate a digital mouse and keyboard and conclude by stating that "[h]igh-bandwidth neural interfaces should enable a variety of novel therapeutic possibilities." In August 2020, Musk reportedly showed reporters a pig whom he claimed had the device surgically planted in her skull (Wong, 2020) and, in February 2021, stated that the device had been planted in a monkey's skull such that the monkey was able to play video games through thought processes (Shead, 2021).

Ethical Issues

Ethics may be defined in different ways, but generally the term refers to an internal assessment of how to behave in the face of conflicting choices. Codes of ethics consist of rules defined by a particular body such as a professional organization that may assist in ethical decision-making.

Any technique associated with controlling behavior requires careful ethical scrutiny. The (over)use of pharmaceuticals springs to mind here. There is an argument that because pharmaceuticals are readily available and open to a wider range of potential misuse than neurointerventions, their use should draw the focus of ethical debate. Over 40 years ago, Samuel Shuman stated (1977: 96):

> Even if we leave aside behaviour modification drugs dispensed by physicians untrained in psychiatry, prescribed for young children by so-called child psychiatrists, and prescribed by pediatricians, it is clear that the number reachable by drugs is enormously greater than the number reachable by surgery.

Nevertheless, techniques targeting the brain raise unique ethical issues because of the psychological or even spiritual significance that is associated with this organ. The notion of the inviolability of the brain may very well be a social construct (Delgado, 1969), but perceptions of the close connection between the brain and mind are such that issues of autonomy and consent need to be carefully navigated. These issues are explored further below.

It is worth noting here, however, that ethical questions also arise as to who has access to and who controls new technology. There may, for example, be an ethical argument for the design of neurointerventions such as implantable brain devices to be publicly shared on the basis that neuroenchantment could be alleviated if information concerning the design of neurointerventions were publicly available.

The concept of open-design relates to the free distribution and permitted modification of products and systems. In a review of current research on open-design, Étienne Boisseau, Jean-François Omhover, and Carole Bouchard (2018) provide the example of RepRap, an amateur-designed 3D printing machine, the documentation for which is freely available on the Internet and which has led to hundreds of customized derivatives. The open-design of brain-computer interfaces, for example, might enable sufficient public scrutiny to address issues with how these devices work.

Another ethical issue relates to possible third-party control of particular neurointerventions. Laurie Pycroft et al. (2016) raise the possibility of “brainjacking,” whereby a third party could control brain implants. They refer to demonstrations of unauthorized control of implantable medical devices such as insulin pumps and implantable cardiac defibrillators to argue that neurosecurity is a valid concern. These matters require further exploration, but the ensuing sections focus on two key ethical issues of consent and autonomy.

Consent

One way of lessening concerns about past controversies and adverse consequences concerning neurointerventions such as psychosurgery and ECT is to ensure that individuals consent to their application. Experimental neurointerventions, as with other novel interventions, are often tried by individuals who have exhausted other forms of accepted or established treatments. They may be desperate to find an alternative “solution” for their impairment. This may indicate that extra caution may need to be taken in relation to obtaining informed consent.

International human rights law provides guidance as to the importance of consent in relation to novel interventions or treatments. Article 15(1) of the United Nations *Convention of the Rights of Persons with Disabilities* (CRPD) sets out that “no one shall be subjected without his or her free consent to medical or scientific experimentation” and Article 25(d) requires “health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent.”

However, a presumption persists that individuals with certain mental impairments cannot make decisions for themselves because they lack a complete understanding of the nature of their impairment. Sometimes, psychiatrists refer to such a lack of understanding as a lack of “insight.” While this is a rather vague term, insight is generally taken to refer to a person’s self-awareness that there is a problem or an illness and an understanding of its cause or meaning (Strauss, 1995: 528). A lack of insight or “poor” insight has been associated with severe mental impairments such as schizophrenia and bipolar disorder, and while theories of the cause of this have ranged from denial to a preference for psychosis, there is a growing literature suggesting that damage to frontal lobe areas may lead to an unawareness of the impairment. This is sometimes referred to as anosognosia (Pia & Tamietto, 2006; Lehrer & Lorenz, 2014).

If a person is unaware, or only partially aware, that he or she has a mental impairment, an argument could be made that consent should be irrelevant; it is in that person's best interests to go ahead with treatment with the aim of improving insight. It could be said that the ends justify the means in relation to the application of neurointerventions that may benefit the individual concerned regardless of whether or not that person consents.

There are, however, criticisms of this approach. The presumption that those with severe mental impairments cannot make decisions concerning their health is one that is subject to debate, particularly in light of recent developments in human rights law. Article 12(2) of the CRPD recognizes that "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life." The exercise of legal capacity reflects a person's right to make decisions and have them upheld by others, as well as the right to stop others making decisions on that person's behalf (McSherry, 2015). Whether Article 12 should be interpreted as preventing substitute decision-making or permitting it in certain circumstances has been a focus of debate by many scholars and clinicians in recent years.

Anna Bruce (2014: 160) notes that the issue of whether health interventions could ever be performed without the recipient's consent was one of the most controversial issues during the negotiations of the CRPD. The Committee on the CRPD (2014: para 41) subsequently addressed the issue of informed consent under Article 25 as follows:

> The right to enjoyment of the highest attainable standard of health (art. 25) includes the right to health care on the basis of free and informed consent. States parties have an obligation to require all health and medical professionals (including psychiatric professionals) to obtain the free and informed consent of persons with disabilities prior to any treatment. In conjunction with the right to legal capacity on an equal basis with others, States parties have an obligation not to permit substitute decision-makers to provide consent on behalf of persons with disabilities. All health and medical personnel should ensure appropriate consultation that directly engages the person with disabilities. They should also ensure, to the best of their ability, that assistants or support persons do not substitute or have undue influence over the decisions of persons with disabilities.

This paragraph suggests that all people, irrespective of their ability or disability, must give individual consent for medical treatment and that substituted decision-making will always be regarded as incompatible with the CRPD. This is reflected in Peter Bartlett's observation (2012: 753) that "the CRPD appears to proceed on the basis that disability cannot be used as a factor in determining whether compulsion may be imposed."

Because of the potential adverse consequences of neurointerventions, it appears preferable to follow the CRPD Committee's interpretation of the relevant Articles in the CRPD and ensure that any neurointerventions only proceed with the person's full and informed consent.

Autonomy

Interfering with the brain raises complex questions about autonomous and responsible agency. Any intervention in the structure or functioning of the brain may affect mental processes, some of which may affect a person's sense of self.

Walter Glannon (2020: 93) points out that autonomy encompasses being able to reflect on the mental states that lead to certain actions, with autonomous agency being "synonymous with the self-regulating process and being in control of one's behaviour." He argues that neurointerventions such as deep brain stimulation can be viewed as supporting a person's ability to be in control of their own behavior by modulating activity in neural circuits. On this basis, neurointerventions may be seen as enhancing or restoring autonomy. Glannon writes (2009: 291) in relation to one case study where a 62-year-old man underwent DBS and experienced a temporary episode of mania, alongside modification of symptoms of Parkinson's disease, that "[f]or the patient, an alteration of his self resulting in less suffering is preferable to a self with more suffering."

With deep brain stimulation and implantable brain-computer interfaces, autonomous agency could be enhanced if the individual had the ability to switch the stimulus on and off or control the frequency to regulate mood, for example (Nicolaidis, 2005). In some ways, the ethical issues that arise here echo those relating to pharmacological interventions for mental impairments. Is the person's sense of self the same with or without drug treatment? A narrative study of a 30-year-old man who received deep brain stimulation for severe obsessive-compulsive disorder points to the need for supports to navigate the uncertainty and intense distress that may accompany a changed identity (Bosanac et al., 2018). Ultimately, it should be up to each individual to weigh up the potential benefits and harms of the suggested neurointervention and sufficient support provided should it be used.

There is an added issue in relation to autonomy of third-party involvement. If someone can manipulate a device implanted in a person's brain, what does that mean for that person's responsibility for ensuing (criminal) actions? Any manipulation might be enough to amount to a mitigating factor in assessing responsibility, but the prospect of "brain-jacking" raises novel ethical issues. In this regard, the Senate of Chile has reportedly approved in its draft constitutional reform the protection of mental integrity in relation to the development of neurotechnologies (Vallat, 2020).

It is beyond the scope of this chapter to consider philosophical issues relating to the prospect of the replacement of neural circuits with a completely artificial human brain, suffice to say that neurointerventions raise ethical issues that require careful consideration beyond the clinical sphere.

Legal Issues

Ethical concerns may be alleviated to some extent by regulation. This can occur through the development of guidelines or the enactment of legislation. In relation to guidelines, for example, with TMS, a group of authorities met in 1996 and agreed on safety and ethical guidelines for clinical and laboratory settings (Wassermann, 1998). These were updated at a consensus conference in 2008 (Rossi et al., 2009).

However, complying with guidelines, policies, codes of practice, and the like is usually voluntary and dependent upon agreement among practitioners. Legislation can be a potent force for compliance because it can provide for both oversight and penalties for not complying with statutory requirements.

Given the history of psychosurgery, there is already legislation in operation in certain jurisdictions to either ban or regulate its use. The use of DBS, for example, is regulated under mental health legislation in certain jurisdictions, while all forms of "psychosurgery" are banned in others.

The inconsistent approach to regulation of psychosurgery is borne out, for example, in Australia in which six states and two territories each has its own mental health legislation. In the Northern Territory, Section 58(2) of the *Mental Health and Related Services Act 1998* states that "[a] person must not perform psychosurgery on another person" and includes within the definition of the term "the use of intracerebral electrodes to stimulate a person's brain" (Section 58(1)). Queensland has a similar provision with a penalty of up to 2 years' imprisonment (Section 241 of the *Mental Health Act 2016*).

In comparison, in South Australia, under Section 43 of the *Mental Health Act 2009,* a Psychiatric Treatment Panel can authorize "neurosurgery" even where the person has not consented, whereas in Victoria, under Section 102 of the *Mental Health Act 2014,* the Mental Health Tribunal can authorize neurosurgery, but only where the person has given informed consent in writing.

It is probably unrealistic to believe there can be consistency in approach to regulating neurointerventions across jurisdictions, but where there is regulation, at least some oversight by an independent body seems appropriate. Legislative provisions can also set out the requirements for full and informed consent and penalties for breaches.

The legislation relating to DBS generally relates to its use in public hospitals. Many experimental neurointerventions are being developed by private companies such as Neuralink which poses a dilemma for lawmakers. Consumer laws can regulate the sale and use of technological devices, but the lack of independent oversight of experimentation by private companies raises concerns about potential harms, even of noninvasive techniques. Adrian Carter, Jamie Walvisch, and Patrick Haylock (2019:2) point out that commercial versions of transcranial direct current stimulation devices that promise enhanced memory and concentration "are not without risk and may cause itching, burns, and headaches and impaired mood, memory and cognition."

Given the history of neurointerventions from trepanation to brain-computer interfaces, it is unlikely that experimentation can be completely banned. It does seem apposite, however, for enough checks and balances to be put in place to mitigate potential harms and unintended consequences.

Beyond Neuroscience and Neurointerventions

Even if ethical and legal issues relating to neurointerventions are addressed, Stephen Morse (2014: 243) has pointed out that “neuroscience has many things to say, but not nearly as much as people would hope.”

Kenneth Kendler (2005: 434–5) has argued that the search for “big, simple explanations” in psychiatry has been doomed to failure:

> We have hunted for big, simple neuropathological explanations for psychiatric disorders and have not found them. We have hunted for big, simple neurochemical explanations for psychiatric disorders and have not found them. We have hunted for big, simple genetic explanations for psychiatric disorders and have not found them.

Even Thomas Insel, the former head of the US National Institute of Mental Health has been quoted as questioning the value of focusing on neuroscience and neurointerventions alone (Rogers, 2017: 1):

> I spent 13 years at NIMH really pushing on the neuroscience and genetics of mental disorders, and when I look back on that I realize that while I think I succeeded at getting lots of really cool papers published by cool scientists at fairly large costs – I think $20 billion – I don’t think we moved the needs in reducing suicide, reducing hospitalizations, improving recovery for the tens of millions of people who have mental illness.

The World Health Organization’s Mental Health Action Plan (2013-2020: 10) acknowledges the need to take “social determinants” into account as one of its key objectives in responding to mental health conditions. Social determinants that are associated with good or poor mental health include the person’s social and cultural characteristics, environmental events, and neighborhood, as well as economic and demographic factors (Lund et al., 2018: 357). Socioeconomic disadvantage, for example, has been classified as a key risk factor associated with experiencing “mental disorders” (World Health Organization, 2014).

Further, there is some indication that public acceptance of neurobiological explanations of mental impairments may increase perceptions that people diagnosed with mental impairments are abnormal and dangerous, thereby increasing discrimination (Lebowitz & Ahn, 2014). Sven Speerforck et al. (2014) found that beliefs about “brain disease” were related to desires for social distance from those diagnosed with major depression or schizophrenia.

The emphasis on mental impairments being caused by something wrong in the brain may also undermine people’s belief in their ability to recover. Erlend P Kvaale et al. (2013) found that biogenetic explanations for mental impairments may induce prognostic pessimism. “Self-stigma” whereby a person internalizes stigmatizing beliefs about mental impairments may also be associated with a failure to seek help (Royal Commission into Victoria’s Mental Health System, 2019: 215).

There are therefore serious consequences associated with studying the brain as a biological machine in isolation from social factors. This adds impetus to ensuring neurointerventions are carefully regulated.

Conclusion

It is simplistic to assume that mental impairments stem solely from misfiring neural circuitry in the brain or that brain-computer interfaces will "solve a lot of brain-related diseases." Henry Louis Mencken (1920: 158) pointed out that "[e]xplanations exist; they have existed for all time; there is always a well-known solution to every human problem—neat, plausible, and wrong."

As history indicates, researchers and clinicians will persist in developing and using technological neurointerventions. For example, despite a complete ban on DBS in certain jurisdictions, it continues to be offered in others. Private companies such as Neuralink are unlikely to give up the search for ways to perfect the brain. While attempts to address mental impairments through some form of neurointervention have long existed, in the past century, there has been a move away from irreversible techniques that destroy brain tissue to reversible invasive and noninvasive techniques.

No matter what further technological developments occur, the main message is that the ethical and legal issues relating to neurointerventions must continue to be discussed and addressed.

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Genetic Engineering and Disability: Ethical Dilemmas in the Verge of Artificial Evolution

67

Francisco J. Bariffi

Contents

Abstract

We are at the cusp of a new revolution shifting from natural to artificial evolution. Recent breakthroughs in genetic engineering opened up a world of new opportunities. The CRISPR-Cas9 gene-editing method allows high-precision cutting and editing of genetic information in the DNA of any living organism, including humans. We have used technology to master nature – now we are about to use technology to change human nature, that has both individual as well as intergenerational applications.

The need for a new regulatory framework is evident. Existing human rights treaties – including biomedical treaties – do not give clear guidance. They were meant to prohibit and control certain things happening to humans but not to deal with humans becoming potentially superhumans or even nonhumans.

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Any new policy conversation and the eventual regulatory regime must be based on the voices of those most directly concerned. Persons with disabilities are among the first to be directly concerned. This chapter explores the basics of the genetic revolution, the crucial ethical implications, and the impact on the rights and dignity of persons with disabilities.

Keywords

Genome editing · CRISPR Cas9 · Bioethics · Disability · Human rights · Disease prevention · Embryonic manipulation · Human evolution

> In our time we are moving out of a world we never made. . .into, for better or for worse, a world of our own creation. (Robert L. Sinsheimer, CALTECH, December 1966)

Introduction

"A crack in creation," (Doudna and Sternberg 2018) "Hacking the code of life," (Carrey 2019) "The gene machine," (Rochman 2018) "Hacking Darwin," (Metzel 2019) "Modern Prometheus," (Kozubek 2018) "Editing mankind," (Davis 2020) and "Babies by design" (Green 2008) all these powerful titles belong to top-selling books dealing with perhaps the most transcendental breakthrough in genetic engineering to date: the CRISPR-Cas9 gene-editing method which allows high-precision cutting and editing of genetic information in the DNA of any living organism, including humans.

The CRISPR-Cas9 gene-editing method has opened the door to a world of new opportunities. Fast, precise, easy, and cheap, this novel method has proven to be applicable in both the somatic and the germline cells of living organisms. As Doudna and Sternberg (2018) attest, "now that science has a cheap and easy-to-use genetic editing tool at its fingertips, we could soon see the rise of precise genetic therapies that usher in a new era of medicine."[1]

Beyond its potential uses for basic research, somatic and germline interventions, genome editing may also be used for genetic "enhancement" – for changes beyond mere restoration or protection of health. As Metzel (2019) states, "at the dawn of the genetics evolution, DNA is becoming as readable, writable and hackable as our information technology."[2]

The notion of editing the genetic makeup of somatic cells – referred to as "gene therapy" – is not new, and some of its legal and ethical implications have already been addressed. However, the possibility of making heritable changes through germline genome editing shifts the conversation from individual-level concerns toward significantly more complex technical, social, and religious concerns

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[1] Doudna and Sternberg (2018). op. cit.

[2] Metzel (2019). op. cit.

regarding the appropriateness of this degree of intervention and how this may affect the acceptance of children born with disabilities (National Academies of Sciences, Engineering, and Medicine 2017, pp. 6–7).

Indeed, CRISP-Cas9 raises serious questions about whether the use of genetic technologies to tackle, and even eradicate, serious diseases and disabilities can be justified and, if so, under which circumstances. Unfettered use of ever-advancing genetic technologies may lead to societal intolerance of disability and genetic difference. Thus, it is necessary to anticipate misuse of genetic technologies and identify potential human rights at stake in order to provide guidelines for governmental regulation (De Paor and Blanck 2016).

As Shakespeare (2015) points out, to "fix" a genetic variation that causes a rare disease may seem an obvious act of beneficence. Nonetheless, such intervention assumes that there is a robust consensus regarding the boundaries between normal variation and disability. There is an urgent need to establish international guidelines and to hear the voices of people living with illness or impairment (Shakespeare 2015).

Genetics in a Nutshell

Since ancient times, humans have fantasized with the possibility to harness God's powers. In Greek mythology, Prometheus, the mankind creator, is punished by Zeus for stealing fire from the Gods and giving it to humanity, an act which enabled progress and civilization. Prometheus is also considered as the creator of science, and perhaps in the dilemma caused by his audacious sin underlies the first ever ethical questioning on the human ability to manipulate nature, including the risks represented by the appearance of Pandora holding the famous box.[3]

Besides the mythological component, in fact, humans have been crafting their ability to manipulate nature for millennia, including breeding of animals and plants. While the foundations of this "organism engineering" can be traced back to the early Phoenicians, it was not until Charles Darwin elaborated his groundbreaking theory "On the Origin of the Species" in 1859 that human understanding of natural and artificial evolution took a leap forward.

In 1864, the Austrian botanist Gregor Mendel, experimenting with plants discovered the patterns in hereditary information, which is passed down from generation to generation settling the building blocks for genetics. Some years later, Dutch botanist Hugo De Vries pushed Mendel's theories further, explaining why genetic differences, or variants, occur in the first place (*mutations*). The work of these three scientists combined to form a complete picture of species evolution (Kean 2013).

Nevertheless, breakthroughs in labs quickly acquired influenced beyond pure scientific endeavor, and in 1883, Francis Galton coined the term eugenics under the belief that selective breeding of human could improve the quality of world

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[3] Kozubek (2018). op. cit.

population (Mukherjee 2017). The Nazi regime took this concept to terrifying extremes including the extermination of thousands of persons with disabilities, an atrocity that prompted the adoption of the first set of research ethics principles for human experimentation known as the Nuremberg Code (Annas and Grodin 1992).

The further discovery of DNA, and most importantly how it works and what it does, led scientists to explore ways to manipulate DNA in order to create new genetic combinations in a lab. In 1953, the protein-manufacturing process of genes was better understood when James Watson and Francis Crick famously discovered that DNA was shaped like a double helix (Watson and Gardner 2015). Furthermore, in the 1970s biochemists Paul Berg and David Jackson achieved the first DNA recombination which paved the way to gene cloning and gene sequencing.[4] Likewise, these breakthroughs allowed in the early 1990s the launch of the most important collective scientific project of all times, the Human Genome Project (HGP).

On June 26, 2000, the HGP announced they had successfully mapped the complete human genome revealing the common ancestry of our species, and much more astonishingly, how genetically close we are to Chimpanzees (98,6% shared genes) (Rutherford and Mukherjee 2018). In this respect, deciphering the human genetic code has unraveled several myths, perhaps the most important, that "as far as genetics is concerned, race does not exist."[5] Likewise, the understanding of how the genome works has helped discover the basis of fatal genetic illnesses (Ridley 2017).

Since the early 1980s, but most efficiently after the HGP mapped the human genome, genetics developed a new technique to fight illnesses named "gene-therapy." In essence, gene-therapy takes the genes the body needs to battle a particular disease and then introduces these genes into diseased cells, effectively stopping the disease.[6] In other words, gene-therapy "corrects or fixes" genetic variation causing diseases throw the genetic manipulation of the body in a living person.

Another development in genetics with huge impact in the genetic makeup of humans was the improvement, accuracy, and accessibility to genetic testing of embryos, especially in the last two decades.

Prenatal genetic testing (PGT) is an umbrella term that includes a number of tests performed on a fetus at varying stages of its development. PGT can be done in the first or second trimester of pregnancy, and they have evolved from invasive and risky techniques to a simple blood sample from the mother.[7] It can be completed in the

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[4] "With DNA, as with words, the sequence carries the meaning, Dissolve DNA into its constituent bases, and it turns into a primordial four-letter alphabet soup." Mukherjee (2017). op. cit.

[5] Idem.

[6] Idem.

[7] Noninvasive prenatal tests (NIPT) can screen for trisomy 21 (Down syndrome) and other chromosomal abnormalities – as well as the sex of the baby – as early as 9 weeks of pregnancy, and with a high degree of accuracy. A few examples available in the market: MaterniT® 21 PLUS, screens for common trisomies (such as trisomy 21, Down syndrome), and can be customized to screen for more conditions (e.g., DiGeorge syndrome); MaterniT® GENOME reports on every chromosome; NACE® Noninvasive prenatal test.

form of screening that can inform expecting parents the chances that the fetus may have certain disorders or chromosomal anomalies.

Preimplantation genetics diagnosis (PGD) is a relatively new technology, first emerging in the 1990s. PGD permits the selection of embryos of a particular genotype prior to implantation in the womb of a woman; it is mostly used to avoid disorders of genetic origin (Knoppers et al. 2006). Two types of PGD are commonly used. The first is a DNA examination that can identify dominant or recessive genes leading to disease-causing mutations. This technology has been marked as a major breakthrough in reproductive therapies for couples who may be carriers of inherited diseases. The second kind of testing commonly performed on embryos before implantation reveals chromosomal abnormalities and can also reveal the sex of the embryo.[8]

Probably, the major breakthrough in genetics came with the discovery of a region of bacterial DNA known as CRISPR (clustered regularly interspaced short palindromic repeats), which can be utilized as a gene-editing tool. In 2012, Jennifer Doudna and Samuel Sternbeg published a groundbreaking paper demonstrating how the CRISPR-Cas9 gene-editing method could be applied to this end (Isaacson 2021). With CRISPR, scientists realized they could harness bacteria to track down and edit genes of our choosing. This has been identified as one of the fastest moving technologies in history with wild implications, such as the possibility of extinct species being revived, or animal genes being edited to grow human hearts and lungs for transplants.[9]

Genetics Through the Lens of Bioethics

Bioethical issues have been intensively discussed at all levels for several decades at the vertiginous rhythm of biomedical breakthroughs. By definition, bioethics is understood as the study of the implications for human beings, in particular human rights and dignity, of the developments of biomedicine. Therefore, bioethics pretend to bring a balance between human action encompassing biological and medical activities linked to advances in biological sciences techniques, and the respect of human rights standards.

Bioethical discussion has led to consensus toward the adoption of basic principles such as autonomy, integrity, identity, dignity, privacy, equity of access, consent, nondiscrimination, justice, and solidarity (Beauchamp and Childress 2019). Unlike other regions of the world, European governance has accomplished the only international legally binding framework to address bioethical challenges (Oviedo

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[8] These tests have been able to reveal the presence of several chromosomal abnormalities such as trisomy 21 (Down syndrome), as well as Turner's syndrome, sickle cell anemia, and cystic fibrosis.

[9] See: *Unnatural Selection*. (2019). Documentary, Directed by Egender, J. and Kaufman, L. https://www.imdb.com/title/tt11063952/?ref_=fn_al_tt_1; *Explained*, S01E02 "Designer DNA." (2018). Documentary, Written by Fong, J. and Gordon, C. https://www.imdb.com/title/tt8453098/?ref_=ttep_ep2; *Human Nature*. (2019). Documentary, Directed by Bolt, A. https://www.imdb.com/title/tt9612680/?ref_=nv_sr_srsg_2

Convention on Bioethics 1997 and the four Additional Protocols – from here on referred as OFC – Oviedo Framework Convention).[10]

The purpose of the OFC is to protect the dignity and identity of all human beings with regard to the application of biology and medicine. Consequently, while the OFC sets forth independent legal obligations, it has necessarily to be interpreted in light of other existing standards of human rights nature, namely, the European Convention on Human Rights (ECRH), and the Charter of Fundamental Rights of the European Union (CFREU) (Nawrot 2018). The inherent links between the OFC and the ECRH has allowed the European Court of Human Rights to address bioethical challenges in several cases.[11]

The systematic interpretation and application of the OFC in the last two decades has allowed European institutions to address ethical and legal challenges raised by developments in the biomedical field, such as biomedical research, human genetic testing and screening, cloning of human beings, xenotransplantation, transplantation of organs and tissues of human origin, and biobanks. Some of these issues have been enshrined in treaties, others in soft law instruments, others in working documents and white papers, and others in case law.[12]

While the OFC has been constantly trying to adapt to biomedical innovations, in recent years, the scope of bioethical issues has significantly expanded due to the development of emerging and converging technologies such as nanotechnology, biotechnology, and information and cognitive technologies (NBICs).[13] Legal and ethical discussions agree that these new and converging NBIC technologies might present challenges in a human rights framework, including areas such as privacy, safety, and autonomy (Van Est et al. 2014; Strand and Kaiser 2015).

In 2015, the Council of Europe (COE) organized an International Conference on "Emerging Technologies and Human Rights" aimed at identifying priority human rights challenges raised by emerging technologies and their convergence, while proposing interdisciplinary debate. The gathering concluded inter alia that science and technology have a growing impact on society and it should be dealt as a matter of priority; that convergence brings together the medical and nonmedical fields; and that current legal framework is inadequate to address issues that are constantly evolving.[14]

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[10] https://www.coe.int/en/web/bioethics/oviedo-convention

[11] *Bioethics and the case law of the Court*. (2012). Research Report, Council of Europe/European Court of Human Rights. Available for downloading at www.echr.coe.int

[12] https://www.coe.int/en/web/bioethics/topics

[13] The phrase "convergent technologies" refers to the synergistic combination of four major "NBIC" (nano-bio-info-cogno) provinces of science and technology, each of which is currently progressing at a rapid rate: (a) nanoscience and nanotechnology; (b) biotechnology and biomedicine, including genetic engineering; (c) information technology, including advanced computing and communications; (d) cognitive science, including cognitive neuroscience. Roco and Bainbridge (2002).

[14] Emerging Technologies and Human Rights, International Conference organized by the Committee on Bioethics (DH-BIO) of the Council of Europe under the auspices of the Belgian Chairmanship of the Committee of Ministers, 4–5 May 2015, Room 1, Palais de l'Europe, Strasbourg. Available at: https://www.coe.int/en/web/bioethics/emerging-technologies#{%2211067078%22:[1]}

In this respect, the Ratenau Report stresses that emerging technologies are seen to go beyond therapy and healthcare, blurring boundaries between medical/nonmedical applications, and between health/illness. The scenarios outlined are generally complex, uncertain, and likely to reach an unpredictable (for some aspects imaginable, for others unimaginable) benefit/risk balance with regard to individuals and society, present and future generations. That is why the question of safety (physical and mental integrity), individual privacy, and social acceptability is generally at the center of discussion, but there is another ethical challenge at stake: the challenge of justice.[15]

At the universal level, there are no binding instruments to address bioethics and genetics, but there are three universal declarations on bioethics and human rights, adopted at the heart of UNESCO.[16] As the lead UN agency in bioethics, UNESCO has been promoting universal bioethical norms and principles, and assisted countries in the translation of those principles to concrete policy outcomes for their citizens.

First, and the most important, is the Universal Declaration on the Human Genome and Human Rights (UDHGHR) of 1997.[17] Art. 1 states that "the human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity." This fundamental statement enshrines the three core pillars, essential in any ethical analysis of genetic development, i.e., dignity, diversity, and heritage. Art. 2 indicates that "dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity." Art.3 clarifies that "human genome, which by its nature evolves, is subject to mutations. It contains potentialities that are expressed differently according to each individual's natural and social environment, including the individual's state of health, living conditions, nutrition and education." Art.10 proclaims that "no research or research applications concerning the human genome, in particular in the fields of biology, genetics and medicine, should prevail over respect for the human rights, fundamental freedoms and human dignity of individuals or, where applicable, of groups of people." Additionally, the UDHGHR also asserts that the "human genome in its natural state shall not give rise to financial gains" (art. 4), ensures the "free and informed consent of the person concerned" (art. 5), prohibits "discrimination based on genetic characteristics" (art. 6), and protects the confidentiality of the "genetic data associated with an identifiable person" (art. 7). Lastly, art. 24 calls for the "identification of practices that could be contrary to human dignity, such as germline interventions."

Second, the Universal Declaration on Bioethics and Human Rights (UDBHR) of 2005 sheds light on the proposed balance between individual rights and science

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[15] Van Est et al. (2014). op. cit.

[16] https://en.unesco.org/themes/ethics-science-and-technology/bioethics

[17] The Universal Declaration on the Human Genome and Human Rights was adopted unanimously and by acclamation at UNESCO's 29th General Conference on 11 November 1997. The following year, the United Nations General Assembly endorsed the Declaration.

referenced in the UDHGHR (Conti 2017). In essence, the UDBHR expands and clarifies the scope of the three foundational pillars enshrined in the UDHGHR. In relation to dignity, art.3 attests that the "interests and welfare of the individual should have priority over the sole interest of science or society," and art.4 declares that the direct and indirect benefits to "individuals should be maximized and any possible harm to such individuals should be minimized." In relation to diversity, art. 13 recognizes that the "importance of cultural diversity and pluralism should be given due regard." In relation to heritage, art. 16 proclaims that "the impact of life sciences on future generations, including on their genetic constitution, should be given due regard," and art. 15 that "due regard is to be given to the interconnection between human beings and other forms of life, to the importance of appropriate access and utilization of biological and genetic resources, to respect for traditional knowledge and to the role of human beings in the protection of the environment, the biosphere and biodiversity."

Lastly, the International Declaration on Human Genetic Data (IDHGD), of 2003, aims to ensure the respect of human dignity and protection of human rights and fundamental freedoms in the collection, processing, use, and storage of human genetic data, of human proteomic data, and of the biological samples. Two fundamental principles relevant to the ethics of gene editing are recognized. On the one hand, each individual has a characteristic genetic makeup, which is part of the person's identity (art. 3). On the other hand, human genetic data have a special status because they can be predictive of genetic predispositions concerning individuals, because they may have a significant impact on the family, including offspring, extending over generations, and in some instances on the whole group to which the person concerned belongs, and because they may have cultural significance for persons or groups (art. 4).

The bioethical implications of the CRISPR-Cas9 gene-editing method are unimaginably vast. In simple terms, this breakthrough allows us to modify, at will, the human genome – a powerful tool for determining our future as a species. Until now, humans have evolved through natural selection, with only some help from external interventions, such as assistive reproductive technologies, but hereditary genome editing with the current level of precision and availability of genetic information may signal a whole new epoch of artificial evolution (AE).

Gene editing in the human germline forces us to step into a very complex zone of the legal and ethical debate, i.e., the "status of the human embryo." Establishing the moral and legal status of the human embryo has been a challenge for researchers, lawmakers, and the international community throughout the past decades (Steinbock 2011). The question of when life begins, and when it begins to receive protection from the law, is contentious and is often influenced by deeply held religious or cultural beliefs. If the bioethical debate over prenatal genetic testing was already extremely controversial, now with these gene editing possibilities it has been pushed beyond its own limits (testing-editing-fixing seems now to be the trilogy covering the whole package).

For this reason, in 2015 an International Summit on Human Gene Editing was convened to explore the many questions surrounding the use of gene-editing tools in humans. In his opening remarks, the chair of the Summit expressed, “we are here as part of a historical process that dates from Darwin and Mendel‘s work in the 19th century. We are taking on a heavy responsibility for our society because we understand that we could be on the cusp of a new era in human history.” The Summit concluded inter alia that genome editing in early embryos or germline cells should not be used for pregnancy.[18]

The same year, the Committee on Bioethics of the Council of Europe released a formal statement emphasizing that – the application of genome editing technologies to human gametes or embryos raises many ethical, social, and safety issues, particularly from any modification of the human genome which could be passed on to future generations. Accordingly, the Committee called to examine the ethical and legal challenges raised by these emerging genome-editing technologies, in light of the principles laid down in the Oviedo Convention on Human Rights and Biomedicine.[19]

Similarly, Jennifer Doudna, Nobel Prize recipient in Chemistry 2020, has repeatedly called to take a prudent path forward (Doudna 2015). Other expert groups have recently published official statements urging caution when using genome editing on gametes or early embryos (The Hinxton Group 2015; National Institute of Health 2015; Progress Educational Trust and Genetic Alliance UK 2017; Mathews et al. 2015).

In 2018, the scientific community was shocked when a Chinese scientist claimed to have created the world’s first genetically edited babies. The researcher, He Jiankui from the Southern University of Science and Technology in Shenzhen, said he had altered embryos for seven couples during fertility treatments, resulting in one pregnancy so far. He said his goal was not to cure or prevent an inherited disease but to try to bestow a trait that few people naturally have: an ability to resist possible future infection with HIV (The Guardian 2018). If corroborated, this trial will be the first known act of human germline genome editing. More recently, a Russian biologist has communicated his desire to create more genome-edited babies (Cyranoski 2019).

These events have accelerated the discussion on the use of genome-editing technologies in humans. The ethical wall built by bioethics in the 1970s to block any heritable modifications of DNA, the “germline wall,” seems to be collapsing. The next wall, apparently still standing, is the wall between disease prevention and individual enhancement (Evans 2018), but further debate is imperative as the transition from somatic genetics (gene-therapy) to germline genetics (genome-editing) is already underway.

Accordingly, CRISPR germline gene editing can be implemented to “edit/fix” so-called “genetic diseases.” Determining the genetic problems that can be subject to this kind of intervention requires ethical consensus. While editing genetic variations

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[18] On Human Gene Editing: International Summit Statement, December 3, 2015. http://www8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=12032015a

[19] DH-BIO/INF (2015) 13, FINAL, Council of Europe, Strasbourg, 2 December 2015.

that cause cystic fibrosis, Huntington's disease, or hemophilia, for example, may be less controversial, the prospective application of genome editing to other variations that cause deafness, Down syndrome, or achondroplasia, for instance, risk raising the bioethical stakes to unimaginable domains and dilemmas.

The use of gene editing in the human germline is as revolutionary and perilous as was control of fire by early humans. The fire certainly allowed *Homo erectus* to keep warm and cook food, but later on in the evolutionary process it was also used to create deadly weapons that have killed billions of humans up to these days. The Prometheus story is as vivid as ever, and humanity seems to be stepping on top of the slippery slope. Has the Chinese scientist opened a Pandora's box?

Genetics, Bioethics, and Disability Rights

The debate over the impact of emerging technologies, and more specifically the one dealing with gene editing of human germline, transcends the classic domains of general human rights to impact significantly on specific groups' rights recognition. While, the bioethical collapsing wall surrounding "eugenics" poses a threat to the general human rights discourse, it becomes particularly challenging in the context of disability rights (Quinn et al. 2016). Over a decade ago (2006), the United Nations approved the Convention on the Rights of Persons with Disabilities (CRPD) which adopted the so-called "social model of disability."(Quinn 2009–2010; Bantekas et al. 2018; Stein 2007) This transcendental legal body is considered as the greatest motor for the paradigm shift from the medical to a social model of disability, and it has been able to establish, as binding obligations, a series of legal standards to eliminate systematic discrimination that persons with disabilities face on their daily life.

In this delicate context, genetic technologies provide a new lens through which we can perceive disability. The ability to prevent a disease or a disability, not only in adulthood but also at the prenatal stage, both challenges traditional and existing conceptions of disability and threatens the human and civil rights of those with current and future disabilities.[20]

Only a handful of academics have tackled these issues. Some view these new technologies as a noncontroversial means of ameliorating or eradicating unwanted impairments (Malek 2010; Savulescu et al. 2016; Harris 2000), while others view these developments as a real threat to the rights of persons with disabilities, as they are concerned with potential discrimination, violations of privacy, and informed consent as well as an erosion of the concept of personhood.[21]

The rapid advance of genetic science has resurrected the specter of eugenics emerging from discriminatory use of genome editing. Indeed, genome editing may facilitate new eugenics of personal choice in health care and reproduction, whereby

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[20] De Paor and Blanck (2016). op. cit. p. 5; Benston (2016).

[21] De Paor and Blanck (2016). op. cit.; Benston (2016). op. cit.; Wolbring and Diep (2016); Conti (2017). op. cit.

humans dictate their own "disability-free" evolution individually and throughout future generations.[22]

Even among disability rights activists and individuals with disabilities, there are diverse points of view. Some fully support potential medical cures, including gene therapy; others focus solely on the removal of social barriers, and others still champion a balance between medical and social interventions.[23] Shakespeare (2013) offers the reassurance that "medical cure or therapy is not incompatible with social change and civil rights: rather than seeing these as alternative strategies, it is possible to see them as complementary." (Shakespeare 2013).

As Benston (2016) points out, "it is hardly fanciful, to consider the counter-intuitive uses to which CRISPR/Cas9 may be put as a method of trait engineering potentially capable of addressing disability in a precise, efficient, and relatively affordable manner. Our continuing debate about whether—and, if so, how—CRISPR should be used and regulated must consider a spectrum of therapeutic approaches running from intentional reduction of disability, to non-interference, to the intentional induction of disability."[24]

Persons with disabilities have long been subject to eugenic practices, including concealment, marginalization, institutionalization, and medical experimentation (Bariffi 2018; Barnes 1997; Abberley 1987). Both theist beliefs and technological development have resulted in a harsh fate for persons with disabilities throughout history (Garland 1995; Stiker 1999). While theists' influence in ethics and law has been gradually decreasing, technological development is clearly on the rise. Therefore, the fears and mistrust of the disability community toward this new therapeutic "impairment fix scenario" are deeply justified. The discourse around genetic editing predominantly adheres to a medical model of the body, disablement, and the "cure sentiment."

Therefore, how we conceptualize disability, human rights, and genetic technologies like human germline engineering and the CRISPR method will frame the regulatory measures we believe are appropriate. Views favoring broad intervention generally argue that such intervention is protected under the right to health and, more specifically, under the right of the prospective child to live above a predetermined reasonable threshold. This view also considers the corresponding duties of potential parents prior to their children's conception.[25] Views favoring restricted intervention generally argue that crucial bioethical issues are involved, and therefore such intervention should be framed under universal (UNESCO universal soft law regime), regional (Oviedo Framework Convention), and domestic bioethical standards which strike a fair balance between biomedical developments and human dignity.[26] Those who are more reserved also advocate for the upholding of universal and regional

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[22] De Paor and Blanck (2016). op. cit.; Lord (2016)

[23] Benston (2016). op. cit. p. 5; De Paor and Blanck (2016). op. cit. p. 7.

[24] Benston (2016). op. cit. p. 3.

[25] Benston (2016). op. cit. p. 8.

[26] Wolbring and Diep (2016). op. cit, pp. 14–16.

human rights standards as stipulated by the UN-CRPD, EU nondiscrimination directives, and domestic nondiscrimination acts – all of which promote human diversity, nondiscriminatory practices, and ultimately, a right to a disability.[27]

It is necessary to establish a holistic and comprehensive approach which accounts for the views and concerns of all relevant stakeholders, with special consideration of voices from the disability community. Compartmentalized legal approaches hamper effective public engagement. In this complex and instable balance between progress and respect for human dignity, we must add a new element of consideration, namely "*human diversity.*" A recent report by the National Academy of Sciences concluded that the distinction between disease and enhancement is hopelessly muddled (National Academies of Sciences, Engineering, and Medicine 2017, pp. 191–192). Therefore, if genetics is to advance irredeemable toward enhancement, the first social group to suffer this consequence will be persons with disabilities. A debate and legal scrutiny about the impact of this scientific development is therefore mandatory.

Framing the Ethical Dilemmas

Concisely, the ethical dilemmas arising from the current development of genetic engineering and disability at embryonic stage (CRISPR germline gene-editing method)[28] can be divided into two main domains, i.e., reproductive genetic disease prevention (RGDP) and reproductive genetic enhancement (RGE). Ethical implications in these two domains seem, at first glance, quite distinguishable. RGDP is about fixing or correcting traits considered as abnormal or undesirable, while RGE is about enhancing or improving "normal" traits. Under this perspective, advancement in the domain of RGDP appears to be ethically justified while advancement in the domain of RGE appears to be ethically unjustified, or at least dubious. As indicated above, under the current state of the art, boundaries between these two domains have become blurry and, probably, undistinguishable.

Reproductive Genetic Disease Prevention

RGDP has evolved at the rhythm of assisted human reproduction (AHR) technologies. In fact, until AHR was possible, RGDP was very limited. Nevertheless, the development of both reproductive and genetic technologies in the last two decades has been exponential.[29]

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[27] Benston (2016). op. cit. p. 12–14; Conti (2017). op. cit. pp. 5–9.

[28] As indicated above, CRISPR gene-editing method can be used to edit and correct genetic traits in both germline and somatic cells. Germline intervention is carried out in the embryonic stage, while somatic intervention can be carried out in the body or a living person, for example, by gene-therapy. For the purpose of this chapter, somatic intervention will not be addressed.

[29] Metzel predicts that IVF will soon be adopted by the mainstream, surpassing sex as humanity's primary method of reproduction by around 2045. Metzel (2019). op. cit.

Current technology allows us to screen and map the genome of a human embryo. In plain terms, it is like getting a detailed blueprint of how that human will look like. That blueprint can also tell us if that human is likely to have genetic disorders. Such technologies include prenatal or preimplantation genetic diagnosis or screenings (PGD-PGT).

The ethical issues raised by prenatal and preimplantation diagnosis differ as the former involves an embryo gestating in a woman's womb; the latter involves an embryo (most commonly several embryos) fertilized and kept in vitro (IVF).[30] However, the ethical issues raised in relation to disability rights are actually the same. Both prenatal and preimplantation diagnosis raise two fundamental ethical dilemmas related to disability rights, i.e., what does "genetic disorder" actually include, and what to do if diagnosis reveals a genetic disorder.

In relation to what does "genetic disorder" actually include, there seems to be general understanding that it refers to genetic variations (mutations) causing diseases and/or disabling traits. It can be a mutation in a single gene (monogenic) or multiple genes (polygenic) or by a chromosomal abnormality. However, the notion of genetic disorder is far from being precise or accurate in terms of science. A genetic disorder is therefore a subset of genetic conditions that give rise to a wide range of characteristics (Nuffield Council on Bioethics 2018). A similar approach can be found in domestic legislations allowing for the interruption of pregnancy when the fetus is a carrier of a so-called "malformation."[31] Coined at the heart of the medical model, the notion of disorder or abnormality has been historically presented, as a scientific truth, when in fact, it is an ambiguous social concept that, most too often, relates abnormality with social undesirability.

The notion of genetic disorder is complex from both biological and social point of view, especially when it is associated with the notion of disease. As a benchmark, it could be argued that a genetic disorder causes a disease when it manifests in ways that significantly affect quality and length of life.[32] Accordingly, for biology a genetic disorder in order to cause disease must manifest beyond the genetic makeup. This is acknowledged in genetics with the distinction between the genotype-phenotype proposed by W. Johannsen in 1911 to make clear the difference between

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[30] This has direct implications in relation to existing laws dealing with interruption of pregnancy. While practice differ considerably from country to country, it appears like legislations are more restrictive in allowing discarding embryos gestating in a mother's womb than discarding embryos fertilized in vitro. Jurisdictions allowing the interruption of pregnancy within the first trimester actually do no distinguish between prenatal and preimplantation testing.

[31] This concept has evolved in recent legislations recognizing the right of the woman to interrupt pregnancy. After the first trimester, interruption is also allowed when "the fetus carries a congenital disorder incompatible with extra uterine life." E.g., Chilean Law 21.030 of 2017; Spanish Organic Law 2/2010.

[32] The notion of quality and length of life also raises substantial ethical issues when used as criteria for the regulation of "assisted dying," or "medical rationing." Bagenstos (2020), Chen and Mcnamara (2020).

an organism's heredity and what that heredity produces.[33] Additionally, modern biology adheres to the notion of "extended phenotype" first proposed by R. Dawkins in 1982 arguing that an organism's phenotype extends beyond its own body to the natural or social environment (genetic environment).[34] Thus, embryonic genetic testing is an indicator of the organism's genotype but not necessarily its phenotype nor its extended phenotype. In other words, genetic testing may be an accurate indicator of genetic disorder in an embryo's DNA, but merely a probabilistic indicator of how that disorder would eventually turn into a disease.

This brings us directly to the social complexity of the notion of genetic disorder and its correlation to a genetic disease. The experience of disability has been inexorably associated throughout history with the notions of sin or sickness, giving rise to stigma and deep-rooted prejudices (Shakespeare 1994; Barnes and Mercer 1996). Goffman affirms that the Greeks "originated the term stigma to refer to bodily signs designated to expose something unusual and bad about the moral status of the signifier." (Goffman 1963) The rise of the medical model of disability somewhere in between the seventeenth and eighteen centuries reinforced the view of disability as a medical condition or abnormality. In contrast to the medical model, disability studies have long argued for understanding disability as a social construct (Stein 2007). The social model shifts the emphasis from individuals with impairments toward restricting environments or disabling barriers. Accordingly, under this perspective, disability is the result from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.[35] This has two major ethical/legal consequences. On the one hand, disability cannot be defined by the individual's impairment, and, on the other hand, the impairment defines the individual's identity and pride. Thus, impairment cannot be associated with abnormality nor with disease, nor it can be considered as intrinsically and/or socially negative or undesirable.

A century ago, the mathematician Karl Pearson coined the discipline of mathematical statistics basing his research mainly in genetics. His controversial theory of biometrical school for inheritance was later used as scientific source by eugenics proponents. As explained in a recent book by Pearl and Mackenzie, Pearson's view was misleading as he failed to acknowledge the adequate distinction and the logical relationship between causation and correlation. Causation indicates that a relationship is one of cause and effect, while correlation implies a connection of sorts between two variables, but nothing more (Pearl and Mackenzie 2018). Acknowledging that data alone can mislead when causality is neglected, these authors developed a process to look beyond the initial observation data called the Ladder

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[33] The Online Mendelian Inheritance in Man (OMIM) is an Online Catalog of Human Genes and Genetic Disorders containing information on all known Mendelian disorders and over 15,000 genes. OMIM focuses on the relationship between phenotype and genotype. https://www.omim.org/

[34] Dawkins notes that when a biologist says something like, "the fruit fly has the red-eye gene," what they really mean is that the fly with this gene is more likely to have red eyes. Dawkins (2016).

[35] Paragraph e) Convention on the Rights of Persons with Disabilities (CRPD).

of Causation. Following this criteria, the authors assert that it is perfectly possible, in contradiction to received wisdom, to establish a logical process to determine when correlation implies a causation. Furthermore, they believe this method could also be programmed into computers so they can answer causal questions.

Purely statistical approaches to establish a logical process to determine when correlation implies a causation should be considered with great prudence, especially if they will eventually be part of Artificial Intelligence algorithms. However, it is important to understand the relationship between correlation and causation in genetic testing. Accordingly, a genetic disorder may have a correlation with a genetic disease but not necessarily a relationship of cause and effect. A genetic disease may have a correlation with a disabling impairment but not necessarily a relationship of cause and effect. Finally, a disabling impairment may have a correlation with social undesirability but not necessarily a relationship of cause and effect. For example, let us compare the genetic mutation causing cystic fibrosis with the genetic mutation causing Down syndrome. Both are genetic disorders, both are genetic diseases if we think of the impact on lifelong health,[36] and both could be considered as disabling impairments as they would be legally regarded as persons with disabilities. However, this does not necessarily mean that they are equally socially undesirable.[37] As noted by Scully, "there is no doubt that genetic factors are involved in illnesses and disabilities, but exactly how they interact with environmental and social factors is likely to differ for every condition. Critics of genetic determinism properly deplore the tendency to ignore non-genetic influences." (Scully 2004).

Human biological and social theorizing on the correlation/causation of the embryo's abnormal genetic makeup and the eventual manifestation of impairment or disease agree upon the need to understand both individual and social/environmental contexts. Therefore, if we cannot understand nor address impairment and disease in a vacuum abstraction, how can we talk about disease prevention in a stage where we only have one of the constituent elements? Some may argue that the current level of genetic engineering allows us to "predict" with great accuracy that a certain genetic disorder will eventually manifest in ways that significantly affect quality and length of life irrespective of any social or environmental context. If we take this pathway, we must agree upon a series of fundamental premises: First, there is no relationship of causation between a genetic disorder and the consideration of

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[36] It should be noted that in the past Down syndrome was considered as a serious disease decreasing life expectancy up to 30 years and the presence of other chronic diseases like heart failure. However, advancement in medicine together with the inclusive paradigm shift of the social model has allowed to improve significantly the health and life of persons with Down syndrome.

[37] "Social undesirable" is used here as a way to think on human traits that we would not hesitate to consider as negative. This does not affect the rights and dignity of persons who actually experience an undesirable genetic disease, like cancer, or Alzheimer's. As Rebecca Cokley stresses out "there is still much desire to put those rendered undesirable in our place." Cokley R (2017). Please do not edit me out. The Washington Post. August 10, 2017. https://www.washingtonpost.com/opinions/if-we-start-editing-genes-people-like-me-might-not-exist/2017/08/10/e9adf206-7d27-11e7-a669-b400c5c7e1cc_story.html

such disorder as socially undesirable; second, the criteria of "significant affection to life length and quality" is not free from controversy in light of human rights standards; third, the criteria of "significant affection to life length and quality" cannot be determined solely in medical or scientific terms, but as result of a social consensus; fourth, there is no possible general rule to determine which genetic disorders are socially undesirable; and lastly, germline gene editing can only be carried out exceptionally in cases of disorders with robust social consensus.

In relation to what to do if diagnosis reveals a genetic disorder, practice shows that both PGD-PGT rely on the so-called "seek-and-destroy" approach, i.e., if a genetic disorder is detected, the embryo is discarded (Boardman 2020). While these technologies have been used in medical practice and AHR for over a decade now, they still pose substantial concerns in light of human rights as they ethically consider the disabling trait more significant than the life of the embryo or fetus (Parens and Asch 2003). Genetic disease prevention technologies raise irreconcilable worries in relation to disability rights and the CRPD itself.[38] We have already been able to see the impacts of the genomic revolution in countries such as Iceland who have almost completely eradicated Down syndrome.[39]

The seek and destroy approach could be labeled as contrary to human rights standards (discriminatory) in those jurisdictions allowing to discard only embryos with genetic disorders, but not in the case of those jurisdiction where the interruption of pregnancy is recognized as a woman's individual right without any further justification than her decision.[40] However, if we dig into disability rights, there is another prominent critique of selective reprogenetic practices known as the "expressivist objection." According to this approach, "selective reprogenetic practices not only prevent disabled people from coming into existence, but that their very availability—and the associated, and often clandestine, social pressures to use them both convey and perpetuate negative views about the particular disabling conditions they are targeted towards, and, by extension, people who currently live with those conditions." (Boardman 2020) Therefore, discarding only embryos with disabling traits could be labeled as contrary to disability human rights standards.

CRISPR germline gene-editing method entails a significant step forward in the domain of RGDP as it allows correcting or removing genetic disorders without the need to discard the human embryo – the seek-and-destroy approach shifts toward a seek-and-edit approach (Cavaliere 2018). At first glance, this major development may present CRISPR germline gene editing as undisputably beneficial and ethically justifiable. However, while overcoming the life-death dilemma of previous RGDP technologies, CRISPR germline gene-editing method creates an entirely new one,

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[38] It should be noted, however, the most dominant view is that human rights protection starts at birth, and therefore, we would be here under a nonruled territory.

[39] Down syndrome in Iceland virtually disappearing, European Down Syndrome Association (EDSA), http://www.edsa.eu/down-syndrome-in-iceland-virtually-disappearing/

[40] Gender rights discussions differ on the approach to harmonize the right to autonomy and the right to access prenatal testing. Johnston et al. (2017), Morton (2015).

i.e., the inheritable impact of this human intervention (Howard et al. 2018). As stressed by Boardman "genome editing, by treating germ cells, not only eliminates genetic variations in the treated embryo, but also makes permanent and heritable changes to the germline that will invariably be transferred to offspring, consequently reducing the incidence of the genetic condition in the human gene pool in ways that currently used technologies are not capable of." (Boardman 2020).

In other words, CRISPR germline gene editing shifts the conversation from individual-level concerns toward significantly more complex technical, social, and religious concerns. Embryonic genetic editing moves away from exclusive individual human rights challenges to step into a new collective and intergenerational human rights scenario. For this reason, some scholars and policy statements acknowledge the need to implement a Human Rights Impact Assessment (HRIA), which captures concerns of public health and offers an opportunity to evaluate and anticipate the societal impact of germline gene editing iteratively as the technology advances, public sentiments evolve, and cultural contexts shift (Halpern et al. 2019). Additionally, given the strong support for the view that the human genome belongs to the world's cultural heritage, HRIA should also embrace cultural and environmental approaches.

The seek-and-edit approach of germline gene editing not only endures challenges to general human rights discourse, but also keeps open the dilemma toward disability rights and diversity. While germline gene editing does not eliminate the embryo per se*,* it does intervene in its genetic makeup in order to eliminate the disabling traits. Consequently, the rationale for expressivist objection argument remains fully applicable, with an additional ethical concern, i.e., the irreversible multiplying impact. For example, let us say we wish to prevent the birth of children with Down syndrome. If we use the seek-and-destroy approach, we would need to discard embryos during gestation or in vitro every time a test detects this genetic mutation, repeatedly. If we use the seek-and-edit approach, we would not need to discard the embryos, but due to the intervention in the germline, after a series of generations and the multiplying effect, that genetic mutation will eventually be eliminated from the human genome for good. This ethical concern is paramount in the discussion of another revolutionary CRISPR gene editing application in plant and animals, namely "gene drives." (Esvelt et al. 2014).

Reproductive Genetic Enhancement

Human germline editing might be used not to eradicate "abnormal" genetic variations per se, but to enhance or improve human traits. Gender, height, eyes, hair or skin color, and muscular structure – the possibilities are endless. The ethical implications of gene editing for enhancement individual traits are so profound that they may even threaten the fundamental building blocks of human rights values, especially considering that the boundaries between fixing and enhancing can easily become blurry. The recent reputed actions of the Chinese scientist leap over both the germline and the enhancement walls (The Guardian 2019).

Concerns about designer babies are very overblown. Complex traits are partly nature and nurture and require hundreds of interactions we do not understand. These complex traits, such as intelligence, are poor targets for technologies like CRISPR, as they are hard to locate within the genome. Currently, only single-cell-carrying diseases can be edited. Using PGD-PGT, cells are removed from IVF and tested for conditions and risks, but the screening can also detect other traits like sex and eye color. It could soon be possible to get a whole genome map at the PGD-PGT stage that could increase the potential for predicting complex traits such as intelligence. These predictions are called polygenic scores and are based on statistical correlations. While they have mostly stayed within academic research communities due to their relative inaccuracy, polygenic scoring may soon be available to the public in fertility clinics.

While still in its early stages, RGE is indeed a reality. If we can edit genes like sex, eyes color, or resistance to HIV, we need urgently to address the ethical implication for human rights in general, and more specifically, in relation to disability or gender rights.

Genetic enhancement was not possible until very recently, so there is limited criteria and only a handful controversial clinical trials. However, the ethical implications of human enhancement have been addressed by ethicists for several decades in the field of biomedicine and, more specifically, in the contentious distinction between biomedical therapy and biomedical enhancement (Harris 2011; Sandel 2009). Likewise, the discussion over transhumanism has resurrected the debate about the ethics over human enhancement in unimaginable ways (▶ Chap. 65, “Transhumanism and Disability”).

At first glance, it would look like genetic enhancement poses a whole set of different ethical dilemmas in relation to genetic disease prevention. Among the trenchant ethical questions of human enhancement are boundaries between therapy and enhancement; differences between normal and abnormal human traits; discrepancies between incremental and radical human enhancements; variations between absolute and relative human enhancements; differences between individual and substituted decision-making; or equality of opportunities in the access to and/or in the socioeconomic impact of human enhancement (Human Enhancement Study 2009).

As de Asís Roig points out, “enhancements raise concerns, which become more serious if persons with disabilities are involved (. . .) the distinction between enhancement and therapy is unclear, but the first problem is that we do not know if there is such a thing as “objective enhancements” (▶ Chap. 65, “Transhumanism and Disability”). Nevertheless, unlike in the context of RGDP, ethical concerns in the context of RGE cut both ways, namely enhancement shall neither be used to edit and eliminate “genetic disabling traits” nor be used to edit and include “genetic disabling traits.” Examples of the former include cases of parents willing to enhance their offspring with genetic mutations causing deafness (Wallis 2020) or dwarfism (Sanghavi 2006).

If we look closer at the core dilemmas underlying human germline enhancement and compare to those dealing with human germline disease prevention, they are actually the same. As indicated above, in RGDP the trenchant dilemmas are how to define “genetic disease” and what to do about it. In RGE, the trenchant dilemmas are how to define “genetic enhancement” and what to do about it. Within the boundaries of what is genetically normal, a genetic disease or genetic enhancement cannot be determined in abstract medical-moral terms, but as the result of social-environmental contexts based on robust societal consensus. Additionally, other indirect ethical questions such as the expressivist objection argument or the impact on equality and nondiscrimination apply equally in both RGDP and RGE (Nussbaum 2002).

Disability right is one among other ethical concerns raised by current and prospect applications of CRISPR germline gene-editing method (Wasserman 2002). However, disability rights reveal the bare bones complexity of genetic interventions in the human genome, and more precisely, the shortcomings of the philosophical attempts to outline general moral imperatives like the “Principle of Procreative Beneficence” (Savulescu 2002; Savulescu et al. 2015) or the safeguards of “informed consent.” (Pinker 2015) Conversely, disability rights show us the need to address germline genetic interventions in the human genome with prudence and a restrictive approach based on robust societal consensus.

Conclusion

We are at the cusp of a new revolution shifting from natural to artificial evolution. Recent breakthroughs in genetic engineering opened up a world of new opportunities. The CRISPR-Cas9 gene-editing method allows high-precision cutting and editing of genetic information in the DNA of any living organism, including humans.

Genetic technology is becoming more prevalent and will inevitably be used in mainstream health care practice. Very soon, when deciding on procreation, parents will face the dilemma of whether to let natural selection take its course or have their gametes or embryos genetically tested, edited, and eventually cleansed of genetic disorders.

While this technology is not yet regulated at domestic level and many of its applications are far from becoming a reality, there is a strong consensus among all relevant stakeholders that we should be having this discussion now. European tradition bears strong support for bioethical challenges, and the systematic interpretation and application of the Oviedo Framework Convention have allowed European institutions to address ethical and legal challenges raised by developments in the biomedical field. This new scenario poses new ethical challenges to the bioethical debate, especially regarding the implications for disability rights and human rights in general.

Germline genetic modification of human gametes or embryos will affect all cells of a resulting child and will be inherited by subsequent generations as part of the human gene pool. This impact is even greater if we use gene drive technologies. Extreme prudence is necessary when altering the human genome; thus, many questions and ethical issues must be assessed beforehand. Artificially altering the human genome will also likely have an environmental impact, and therefore valuable insights can be obtained from existing environmental protection frameworks.

Environmental law principles such as "sustainable development," "environmental impact assessment," or the "precautionary principle" may be of great relevance regarding this topic.

We have used technology to master nature – now we are about to use technology to change human nature. That has both individual as well as intergenerational applications. The need for a new regulatory framework is evident. Existing human rights treaties – including biomedical treaties – do not give clear guidance. They were meant to prohibit and control certain things happening to humans but not to deal with humans becoming potentially superhumans or even nonhumans.

Would it be possible that science could actually fix disabling impairments? Or instead, this new impairment-fix scenario could simply allow the rebirth of the medical model of disability and accordingly a shift backward on disability rights recognition and enjoyment? Will the future foresee the birth of a new human/ artificial category?

Any new policy conversation and the eventual regulatory regime must be based on the voices of those most directly concerned. Persons with disabilities are among the first to be directly concerned. These lesser-heard voices are likely to be absent unless conspicuous space is given to them now.

Crucial questions arise which will need to be dealt with both within and beyond the disability community. Is there a right to be disabled? Can we (parents) impose disability on our offspring? How extensive is the amplitude for prevention (option-duty)? Does the UN-CRPD enshrine particular obligations beyond existing bioethics instruments? What weight exactly is to be given to the collective voices of persons with disabilities in the process?

As we walk toward this transcendental human debate, we need to ensure the rights of persons with disabilities. This introductory chapter offers some basic fundamental premises to address CRISPR human germline interventions' prudence and a restrictive approach based on robust societal consensus while rejecting approaches based on general moral imperatives.

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Power, Personhood, and Data-Driven Technologies in the Lives of Disabled People: The Rise of Profiling Technologies in Mental Health Settings

68

Piers Gooding

Contents

Abstract

This chapter examines the rise of biometric monitoring using AI and other automated decision systems in the disability and mental health context. It focuses on the use of "digital phenotyping" or "behavioral sensing" in settings as diverse as hospitals, community-based services, and homes, in criminal legal settings, and among direct-to-consumer products. The chapter surveys prominent critique of the impact of data-driven observation and surveillance for the general population, as well as the small but emerging literature on its effects on disabled people in particular. It explores the potential implications of biometric monitoring on individual dignity and personhood but expands the focus to collective concerns beyond an individualistic focus on the rights of data subjects. To reflect on these implications, the chapter brings together scholarship on algorithmic accountability, the Convention on the Rights of Persons with Disabilities, and Michel Foucault's "panopticism." The chapter makes the case for the active involvement of people with disabilities in the governance of automated profiling systems and the scientific discourse that drives them. Governance would encompass the

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identification of harmful social consequences, as well as identifying benefits that may emerge and helping to adjudicate any societal trade-offs that may be required to achieve them.

Keywords

Artificial intelligence (AI) · Algorithmic accountability · Disability · Digital phenotyping · Machine learning · Mental health

Introduction

Some of the biggest ethical and legal debates on personhood in recent decades concern medical technologies designed to ameliorate disability and human impairment. Examples include prenatal screening for fetal chromosomal and genetic conditions and somatic cell gene therapy. “Disability” and “impairment” carry great normative significance in these debates. They remain entwined in conceptions of the person and in the practices, forms of governance, and scientific discourse that shape them. Automated and data-driven systems have started to extend and transform these concerns. Yet, according to Meredith Whitaker and colleagues, disability has been omitted from most discussions about artificial intelligence (“AI”) and other automated technologies (Whittaker et al., 2019). This chapter brings them to the fore.

It will focus on profiling technologies built on biometric data and automated decision systems. I will focus on the mental health context and the increasing experimentation with practices like “digital phenotyping” and “behavioral sensing” in psychiatry and psychology. Although scholars have articulated the implications of persistent observation and surveillance for the general population, including linking harms to privacy’s concern for defending individuality and personhood against the state and the market, this chapter will extend those concerns to the disability context, including asking what collective concerns may be raised and addressed beyond an individualistic focus on data subject rights (Viljoen, 2021). The chapter will seek to expand the examination of personhood and its uncertain future in the digital age by bringing together two strands of scholarship: one from law and technology, concerning “algorithmic accountability,” and the second from disability and law, concerning the Convention on the Rights of Persons with Disabilities (CRPD).

“Algorithmic accountability” has been promoted by some scholars to promote basic standards of algorithmic and technological transparency and auditing, but it also takes the opportunity to ask more fundamental questions like whether or not to use automated and digital systems in the first place in some circumstances and, if they are to be used, who should govern them (Pasquale, 2019). These issues are increasingly relevant following the COVID-19 pandemic, which has not only driven more of our lives online but has accelerated the digitization of various public services worldwide, including disability and mental healthcare services (Torous et al., 2020), and seen the expansion of private digital infrastructure throughout societies.

The CRPD, as is now well established, is premised on a rejection of the “view of persons with disabilities as objects of charity, medical treatment and social protection" (Arbour, 2006). The CRPD instead seeks to affirm them as "subjects of rights, able to claim those rights as active members of society" (Arbour, 2006). From this view, the idea of disability as one aspect of human diversity is affirmed by "respect for difference and acceptance of persons with disabilities as part of human diversity and humanity" (Degener, 2016). The CRPD sets standards for society where politics and law need to be fashioned around a complete, comprehensive vision of the human experience, of which disability is a natural part. Although the CRPD may appear at first glance to advance individualist justice claims, as per a common characterization of human rights, the CRPD has collective dimensions driven by a relational perspective on disability which views socioeconomic conditions as constitutive of disability itself.

To draw the threads of the CRPD and algorithmic accountability together, this chapter first articulates key terms to help frame the discussion. Defining "data concerning disability" is difficult, particularly given the rise of data that can be used as a proxy for a person's impairment or disability. To navigate this complexity, I will draw on key concepts from the European Union General Data Protection Regulation (GDPR) given its prominent place in contemporary data protection law (and notwithstanding critique of its relative merits). The CRPD provides an expansive, de facto definition of persons with disability that can also help reflect on how disability-related data might be conceptualized and, in turn, governed. The second section considers the expansion of profiling technologies and biometric data generation in the mental health context. It includes a range of examples, from direct-to-consumer products to largescale clinical and computational research for interventions in hospitals, community-based services, and criminal legal settings. The third section surveys critical engagement with these developments, exploring issues of justice and power and drawing on Michel Foucault's theorization of "panopticism." The final section seeks to move the discussion away from a focus on profiling technologies themselves and toward questions of who is benefiting and losing from their adoption. As with other chapters in this collection, I stress the active involvement of people with disabilities in governance, but I stress that this is particularly important in the context of automated and data-driven systems for exposing and addressing the potentially harmful social consequences of automation for all, including identifying the benefits that are possible and helping to adjudicate any societal trade-offs that may be required to achieve them.

A Note on Terminology: "Data Concerning Disability, Health, and Mental Health"

Finding clear terminology in areas of rapid technological change can be tricky. I will use "automated and data-driven systems" here to cover diverse technologies that use contemporary computer processing to analyze large amounts of data algorithmically, including via AI, machine learning, neural networks, deep learning, predictive analytics, natural language processing, robotics, speech processing, and other forms of automation used to making decisions (Castelluccia et al., 2019). These technologies will be considered in the context in which they are applied, including the people who use them – hence, referring to automated and data-driven systems rather than dwelling on the technology in isolation.

Some data-driven systems do not explicitly use sophisticated forms of AI and automation (e.g., electronic records management software or care labor platforms) but remain relevant, as they form part of a broader communication ecosystem that can generate and transmit data concerning human activity. "Communication ecosystem" refers here to the complex, global networks of information and communication technology, which encompasses disparate systems, such as the web, the Internet, and various public and private intranets, including those used by service providers, private data brokers, and welfare system operators. These systems are increasingly converging to create massive, complex, and interconnected flows of data.

Language concerning disability-related data also remains unsettled. A narrow view could suggest "data concerning disability" is individual in character, related to the clinical reporting of impairments, such as through medical records, functional assessment results, and so on. No one would deny the sensitivity of such data. Yet the CRPD clearly calls for a more expansive approach. The CRPD was strongly influenced by the social model of disability and arguably a newer "human rights model" of disability (Degener, 2016), both of which emphasize the social and physical barriers to disabled people's inclusion on an equal basis with others. This would mean that relevant "disability-related" data and information could come from an array of sources that reflect the ways disability is constituted by people's impairments in interaction with social and physical barriers to their participation in society. By way of example, this could include data that could be used to infer disability, such as a person's consumer transactions concerning particular medications or accessibility products, like hearing aids or prostheses.

Importantly, the CRPD covers people who experience harms due to *imputed* impairment or disability (CRPD, Arts 2, 4, and 5). This component of disability is important here because some automated decision systems purportedly function to deduce a person's impairment, including *inferring* matters like mental health conditions, dementia, and other cognitive impairments. At the time of writing, for example, Apple is working with multinational biotechnology company Biogen and the University of California Los Angeles to experiment using mobile device sensor data (such as mobility, apparent sleep patterns, and swiping patterns) as behavioral proxies to infer mental ill-health and cognitive impairment (Winkler, 2021).

Regardless of the accuracy of such predictions, there remains the very real likelihood that these practices will result in bias, discrimination, and other harms against people based on such data – again, whether or not *those data are false, misleading, or inaccurate*. To give a concrete example, advocacy group *Article 19* recently surveyed 27 Chinese companies whose emotion recognition technologies are being trialed in public security, driving safety, and educational settings (Emotional Entanglement, 2021). Companies like Taigusys Computing and EmoKit refer to autism, schizophrenia, and depression as conditions they can diagnose and monitor using "micro-expression recognition." The authors of the *Article 19* report observe that both the scientific basis for these claims and the harms that may arise concerning mental health remain unaddressed:

> While some emotion recognition companies allege they can detect sensitive attributes, such as mental health conditions and race, none have addressed the potentially discriminatory consequences of collecting this information in conjunction with emotion data... Firms that purportedly identify neurological diseases and psychological disorders from facial emotions fail to account for how their commercial emotion recognition applications might factor in these considerations when assessing people's emotions in non-medical settings, like classrooms. (Emotional Entanglement, 2021)

Traditional facial recognition processes based on "basic emotions theory" have been discredited as pseudoscientific (Feldman Barrett, 2017), and there is no evidence to support the claims of companies like Taigusys Computing. But for the purposes of defining "data concerning disability," it is irrelevant – such credibility gaps would not necessarily prevent harm to those reported by those systems to be cognitively impaired.

The wide definition of disability implied by the CRPD highlights that *all* persons – disabled and non-disabled alike – may interact with systems that generate data concerning disability, whether real or imagined. In the context of psychosocial disability, for example, if you carry a smartphone into a therapy service, visit a depression information website, write about distress on a social media platform, or even simply type and scroll on a mobile device in certain ways, then various "digital trails" will be generated that could be used to infer particular states of psychiatric disorder, distress, and cognitive impairment (Metz, 2018; Schneble et al., 2020; Wang et al., 2015).

This is not to endorse or accept such claims. Indeed, I will later critique the common claim that computational data can easily or neutrally represent reality, let alone "reveal" people's inner worlds. Instead, the point here is to reiterate that the rise of big data and automated decision systems has increased the likelihood of *inferences* and *predictions* being drawn from the behaviors, preferences, and private lives of individuals, which has important implications concerning disability. In the health context, these data have been described variously as "emergent health data" (Marks, 2020a) or "indirect, inferred, and invisible health data" (Schneble et al., 2020). Mason Marks proposes the term "emergent medical data" given that "digital traces have emergent properties; [and] when analyzed by machine learning, they reveal information that is greater than the sum of their parts" (Marks, 2020b).

As has been well established, these forms of inferred data create new opportunities for discriminatory, biased, and invasive decision-making about individuals and populations (Wachter & Mittelstadt, 2019). Thus, the type of profiling technologies discussed in this chapter raises issues that affect everyone. However, notwithstanding this universal relevance, high-risk applications of profiling and biometric technologies are likely to have the greatest impact on people who are presently marginalized. In the mental health context, this could include service users or those who are subject to involuntary mental health interventions, social security recipients, people in the criminal justice systems, and those facing intersecting forms of socioeconomic marginalization.

Given this chapter is concerned with profiling technologies in the mental health context, I will use the term "data concerning mental health." This term is taken to mean personal data related to the mental health of a person, including the provision of health and social care services, which reveal information about a person's mental health status. ("Data concerning disability" could be defined the same way, where "disability" replaces "mental health.") This definition draws on the European Union GDPR, which explicitly does not include the term "health data" and instead uses the broader phrase "data concerning health." "Data concerning health" is defined at Article 4(15) as "personal data related to the physical or mental health of a natural person, including the provision of healthcare services, which reveal information about his or her health status." Christophe Schneble and colleagues argue that this important distinction "opens the door to indirect and inferred health data falling within the scope of the GDPR" and therefore strengthens its application outside as within the formal healthcare system (Schneble et al., 2020). It is too early to determine the extent to which Schneble and colleagues are correct, and the GDPR remains subject to a wide field of debate.

Indeed, others remain skeptical that even leading data protection laws like the GDPR can sufficiently protect people in the mental health context against the full range of the harms that may arise. Nicole Martinez-Martin and colleagues refer to the potential misuse of inferred data concerning mental health, arguing that existing regulations, including the GDPR, "do not address or sufficiently protect individuals from companies and institutions drawing health inferences from personal data" (Martinez-Martin et al., 2021). They warn of insurance and employment discrimination and argue that "even clinical, *regulated* applications . . . present significant concerns regarding transparency, consent, and the distribution of risks and benefits for patients and users regarding how their data may be shared and used" (Martinez-Martin et al., 2021). Even where data protection laws are violated, enforcement remains an issue. For example, a Privacy International investigation showed how popular mental health websites in Western Europe were in clear breach of the GDPR, but enforcement was lacking, and breaches continued several months after the initial violation was exposed (Privacy International, 2021).

Questions remain about what exactly would fall within the definitions of data and information concerning mental health and disability, which seem likely to be a source of ongoing debate (see, e.g., Fisher & Appelbaum, 2017). Suffice to say that the rising use of such data is blurring the boundaries between "patient," "service user," "consumer," and "citizen," creating multiple issues around the commodification and commercialization of health, the rise of "bio-surveillance," and other issues which have profoundly implicated disabled and non-disabled people alike.

Profiling Technologies and Biometric Data Generation in the Mental Health Context: A Growing Industry and Scientific Practice

The GDPR defines "profiling" in Article 4(4) to mean:

> any form of automated processing of personal data consisting of the use of personal data to evaluate certain personal aspects relating to a natural person, in particular to analyse or predict aspects concerning that natural person's performance at work, economic situation, health, personal preferences, interests, reliability, behaviour, location or movements.

One means of profiling is via "biometric data," defined as:

> data resulting from specific technical processing relating to the physical, physiological or behavioural characteristics of a natural person, which allow or confirm the unique identification of that natural person, such as facial images or dactyloscopic [or fingerprinting] data. (GDPR, Article 4(14))

Various forms of profiling occur that generate biometric data in the disability context, raising many ethico-legal issues given the insights such technologies are purported to reveal about a person's health, body, cognition, affective state, and so on (Cosgrove et al., 2020a; Kak, 2021; Martinez-Martin et al., 2018). Biometric monitoring technologies use sensors in devices, including smartphones, "wearables," and cameras, and even in pills to generate and process data concerning a person's biology, physiology, or behavior.

There are various ways to describe such technologies. Computer scientists may refer to "context sensing," "personal sensing," or "mobile sensing." Mental health researchers have begun to refer to "digital phenotyping," particularly in relation to the assessment of behavior, mood, and cognition through biometric data generated by devices, such as smartphones and FitBits (Insel, 2017). An advertisement for the prominent direct-to-consumer app company, Mindstrong, for example, describes how the app is supposed to function:

> How you passively use your smartphone – typing, swiping, scrolling – is a new way to measure things like your stress, mental health symptoms, and well-being. If you're typing more slowly – even by a millisecond – it might mean there's a change. You can track your measurements in the mobile app, and they're shared with your clinical team so they can provide you with more personalized care. (Mindstrong, 2021)

Some mental health practitioners are enthusiastic about the "enormous potential" of this technology "to improve our understanding of the experience of individuals and our capacity to deliver behavioural health treatments" (Mohr et al., 2020). This potential could include the integration of monitoring apps into standard psychological treatments (e.g., apps that monitor behavior may be prescribed alongside talking therapy), the delivery of biometric monitoring as a standalone intervention, as well as using "[p]assive tracking of populations of at-risk people" to facilitate "early identification and intervention for behavioral problems" (Mohr et al., 2020).

In 2021, for example, up to 20,000 Australian high school students were to have their phone data monitored for up to 5 years in a trial aimed at tracking how mental health issues develop in adolescence (Black Dog Institute, 2021). According to the researchers, "[t]he study aims to discover how we can use smartphones to deliver preventive interventions on a large scale" and makes use of "[c]omprehensive, technology-assisted data collection and analysis [...] to determine what triggers the development of mental health symptoms" (Black Dog Institute, 2021). The authors report that no study of mental health apps has occurred at this scale anywhere in the world (Black Dog Institute, 2021). Many of the children and young people involved in the study would reportedly interact with game-based apps, have their movement and location tracked, and be asked specific questions about their state of mind, including whether they have contemplated suicide.

Forensic mental health settings are also deploying automated decision systems used to classify human behavior. In 2015 in Austria, for example, ten patients in a psychiatric hospital were given a mobile phone with an app that was "based on smartphone behavior and activity monitoring" over a 12-month period (Grünerbl et al., 2015). The app generated data that was "usable [by clinicians] as an 'objective' measurement that help[ed] detect state changes to guarantee the availability of in-time treatment" (Grünerbl et al., 2015). Researchers compared evaluations using standard scales (such as the Hamilton Depression Scale) with patient mood using sensors based on phone use, voice activity, and bodily movement. The findings indicated a "state change detection precision and recall of over 97%" (Grünerbl et al., 2015), suggesting almost perfect accuracy.

In acute psychiatric settings, computer vision has been developed that monitors patients using remote (and not on-body) sensors. In 2020, "digital assisted nurse observations" were trialed in a psychiatric ward in England (Barrera et al., 2020). This practice has been variously described as "video-algorithmic patient monitoring and surveillance," "artificial intelligence-enabled audio-visual surveillance and monitoring," "vision-based patient monitoring and management," and "digitally assisted nursing observations." In the English trial, the monitoring was used by nurses to take 15-minutely and hourly night-time "clinical observations" of patients in 6 individual bedrooms over a 4-month period (Barrera et al., 2020). The sensors used by researchers were wall-mounted video cameras along with "computer vision, signal processing, and AI software" that enabled nurses to track their patients' locations and movements ("physical monitoring") and to record their heart and respiratory rates ("physiological" or "vital sign monitoring"), all from a centralized nurses' station (Lloyd-Jukes et al., 2021). Physiological monitoring using the system allows nurses to access "real-time spot measurements of pulse rate and breathing rate without them having to enter the room" (Lloyd-Jukes et al., 2021). The software reportedly generates long-term information in the form of "a timeline summarising the patient's location (in bed, elsewhere in their room, etc) for a day or a week . . . to help characterise the patient's behaviour during that time interval" (Lloyd-Jukes et al., 2021). The use of these systems is reportedly expanding, with the company that produces them reporting that they are "relied on by one in three English mental health trusts as well as acute hospitals, care homes, skilled nursing facilities, prisons and police forces in the UK and Europe" (Oxehealth, 2021).

Other forms of biometric sensing go "beneath the skin," where ingestible sensors have been integrated with psychopharmaceutical pills (Flore, 2021). For example, in 2017, the US Food and Drug Administration ("FDA") approved a so-called digital pill (FDA, 2017). "Abilify MyCite," as it is commercially named, integrates a pill with an electronic sensor. The sensor is activated upon contact with a person's stomach fluid. Information concerning the nature and timing of ingestion is then transmitted via a patch worn on the skin to a linked device, such as a smartphone. Family members, clinicians, and other third parties can attain the information generated about the ingestion, with the person's consent, through a web-based portal. The smartphone/tablet app can also track "self-reported measures of rest and mood," though the pills are advertised primarily as “targeting the problem of medication adherence” (Klugman et al., 2018). According to the FDA, “Abilify MyCite” is aimed at “the treatment of schizophrenia, acute treatment of manic and mixed episodes associated with bipolar I disorder and for use as an add-on treatment for depression in adults” (FDA, 2017). Digital pills have also been approved for use by regulatory bodies in China and the European Union.

Proponents of such technologies view biometric monitoring with therapeutic aims as a novel method for real-time clinical monitoring that, for some people, may improve therapeutic outcomes for people with mental health conditions and psychosocial disability. This enthusiasm is typically accompanied by acknowledgement that some patients will not want to use nor gain from such measures, as well as occasional acknowledgements that the practice gives rise to unresolved ethical issues (see Gooding & Kariotis, 2021).

Troublingly, the practice has been proposed in highly prejudicial forms of state intrusion into the lives of people with mental health conditions and psychosocial disability. Senior members of the former Trump administration, for example, including then President Donald Trump and Vice President Mike Pence, were briefed on a proposal, “SAFEHOME – Stopping Aberrant Fatal Events by Helping Overcome Mental Extremes,” that would involve experimentation into whether “technology including phones and smartwatches can be used to detect when mentally ill people are about to turn violent” (Wan, 2019). The proposed new research would sit within a proposed new US department of health division, the “Health Advanced Research Projects Agency,” to be modelled after the Defense Advanced Research Projects Agency (or DARPA).

Although SAFEHOME was not adopted during the Trump presidency, it suggests that ideas about biometric monitoring lie in proximity to preventive policing policies and forms of algorithmic risk management. Other technological experiments have seen police and border authorities generate and process mental health-related data from disparate public and private systems. In 2018, for example, the Florida state legislature authorized the collection and digitization of certain types of student mental health data and its distribution through a statewide police database, intended to prevent gun violence (Travis, 2019). The same year, municipal police in Canada collated non-criminal information about individuals who had self-harmed or attempted suicide (Canada, 2017). The information – which it should be noted was *not* biometric data but rather typical police records – was then circulated to US border authorities, who used it to deny several Canadians’ entry into the USA (Canada, 2017). These examples, too, highlight the growing potential for profiling technologies and mental health-related databases to be used in prejudicial targeting by state authorities.

Power and Justice in the Biometric and Digital Turn

Given the above, serious concerns can be raised about the rise of profiling technologies that generate and rely on biometric data in mental healthcare. One obvious point is that even where good faith efforts are made to develop biometric monitoring techniques that individuals want to use, and even if those efforts manifestly benefit them as individuals, there is the potential for these same techniques to have extremely deleterious effects on broader populations. Consider the following comment by Neguine Rezaii:

> [w]hen I published my paper on predicting schizophrenia, the publishers wanted the code to be openly accessible, and I said fine because I was into liberal and free stuff. But then what if someone uses that to build an app and predict things on weird teenagers? That's risky. [. . .] [Open science advocates] have been advocating free publication of the algorithms. [My prediction tool] has been downloaded 1,060 times so far. I do not know for what purpose. . .. (Adam, 2020)

It is uncontroversial to say that biometric monitoring, as an exploratory technique in mental health sciences, has a highly limited evidence base demonstrating its real-world benefits, even if control conditions might suggest positive outcomes. Yet, the potential for it to be used in unexpected and harmful ways under current conditions suggests serious caution is needed, particularly given mental health-related data appears to very poorly governed and protected in the information economy writ large (see Bossewitch et al., 2022).

A key set of concerns hinge on contested claims about what "digital markers" of behavior can reveal about a person (see, e.g., Fisher & Appelbaum, 2017; Friesen, 2020). These concerns tend to fall into well-worn debates in the mental health context about behaviorism (which, crudely put, tends to prioritize the external behavior of individuals and view external stimuli as the primary locus of behavior) versus psychoanalytic approaches (which prioritize the mind and the subjective search for meaning and view the unconscious as potentially motivating behavior) (Pasquale, 2021). A behaviorist perspective, for example, might suggest that biometric monitoring offers a *more* reliable measure than existing approaches in mental healthcare that are based on the subjective reports of individuals or the subjective observation of mental health practitioners. Data that serves as a proxy for a person's behavior, from this view, could serve as "objective parameters that correlate with mental health status" (Resnick & Appelbaum, 2019). A more psychoanalytic viewpoint would seemingly balk at the way such a view undermines the "reliable narrator" in this picture – that is, the person themselves and their evolving perception of their inner lifeworld in the social context in which they live. The tension between these viewpoints echoes throughout the literature, as the remaining discussion will show.

Terminology is unsurprisingly contested. David Mohr and colleagues criticize the very term "digital phenotyping" for failing to convey the reality that the practice constitutes surveillance over intimate aspects of a person's life (Mohr et al., 2020). They suggest that the term "does not convey to the average person that we are engaging in a sensitive form of surveillance: collecting large amounts of data, and using those data to understand deeply personal things, such as how they sleep, where they go, how and when they communicate with others, or whether they may be experiencing a mental health condition" (Mohr et al., 2020). The authors ultimately endorse the practice itself but call for language that is more transparent about its intent, arguing the term "personal sensing" is more appropriate (though one might query whether "personal sensing" offers a clearer explanation).

Others reject the practice as inherently harmful, at least under current social conditions, drawing attention to issues of justice and power that come with persistent observation and surveillance (Harris, 2019). Leah Harris warns of biometric technologies being used in forms of social control over marginalized individuals, not just in mental health settings but also in prisons and other sites of carceral control, including in people's homes and communities (Harris, 2019, 2021). Harris draws on Michel Foucault's theorization of the panopticon, discussing the power gained by "both the ability to observe others and the knowledge obtained through that observation" (Harris, 2019). As is well covered elsewhere, the panopticon was originally an architectural system developed in the eighteenth century by Jeremy Bentham designed to continuously observe prisoners in confinement. For Foucault, *panopticism* refers to a metaphor or analytical tool to describe the surveillance mechanism used to exert disciplinary power throughout society by professionals, bureaucracies, government agencies, market actors, and so on by allowing for an "absolute and constant visibility surrounding the bodies of individuals" (Foucault, 2006).

Toward the end of his life, Foucault conceptualized a shift in Western societies away from the dominance of disciplinary environments, such as largescale psychiatric institutions, to systems of constant external surveillance. He wrote that "[o]ne also sees the spread of disciplinary procedures, not in the form of enclosed institutions, but as centres of observation disseminated throughout society" (Foucault, 1995). Foucault charts these societal shifts toward forms of control that are less costly and complex to manage than large asylums (Paradis-Gagné & Holmes, 2022). For Harris, biometric monitoring in the mental health context constitutes panopticism by virtue of the power asymmetries between the "'omnipresent' and 'invisible' watchers and their 'permanently visible' subjects," which Harris argues is an extension of the historic role of psychiatry as a science in governing "troublesome" populations (Harris, 2019).

It may be that these power asymmetries can be addressed through careful consent processes at the individual level, but others raise concerns about the collective harm that result from automating mental health classification in this way. For Jonah Bossewitch (2019) and others, these harms are particularly likely under the current economic conditions variously characterized as surveillance capitalism, platform capitalism, and so on. (see eg, Zuboff, 2019, Jeff Nagy, 2022), for example, suggests that disability has been transformed in the past two decades "into a rhetorical, conceptual, and material resource for the expansion of surveillance capitalism." For Nagy:

> This history has also underwritten a larger reconceptualization of emotional data, from a neglected variable in human-computer interaction to an exploitable corporate asset, a transformation that has allowed platform users' emotional lives to be mined for new forms of knowledge, value, and power. (Nagy, 2022)

Likewise, Lisa Cosgrove and colleagues suggest that "mental health apps that use digital phenotyping and other surveillance technologies position people as unwitting profit-makers . . . [by taking] individuals at their most vulnerable and make them part of a hidden supply chain for the marketplace" (Cosgrove et al., 2020b).

Tying these concerns to longstanding critique of the professional power of psychiatry, Bossewitch (2017) has warned of the "arrival of surveillance psychiatry." He queries the role of biometric profiling in the growing information economy, whereby "huge pools of data are being used to train algorithms to identify signs of mental illness" (Bossewitch, 2017). It remains to be seen how extensive such profiling will become and how it will be governed under the new era of data protection laws such as the GDPR. As an example of the kind of limitations the GDPR imposes, Article 22 of the GDPR states that "the data subject shall have the right not to be subject to a decision based solely on automated processing, including profiling, which produces legal effects concerning him or her or similarly significantly affects him or her." Bernadette McSherry has noted that predicting aspects of a person's mental health appears likely to fall within the ambit of this article, offering the potential for protection (McSherry, 2018).

Beyond legal remedy to prevent data-driven and automated systems of diagnosis or proxy diagnosis, commentators often premise their concerns about profiling technologies with a broader challenge to computational ways of knowing, which ties to critiques of behaviorism noted earlier. Arguably, there is a commonly held view that computational monitoring, measurement, and evaluation of people *necessarily* afford access to knowledge about individuals, including their inner state. However, computational technology may well *get in the way* of understanding people, including the unique experience of each new person in crisis or distress who deserves to be heard fully. Research by Victoria Hollis and others, for example, suggests that people who use algorithmic interpretations of data concerning emotions can be misled about the extent to which such systems can "capture" the reality of emotional experiences (Hollis et al., 2018). Hollis and colleagues surveyed 188 people who showed strong interest in automatic stress and emotion "tracking," with the results indicating that "many respondents expected these systems to provide objective measurements for their emotional experiences" despite this simply not being possible (Hollis et al., 2018).

This framing effect (which is often exaggerated by vendors of technologies who are trying to sell their product) can even change the way people construe their own emotions. In a second study, Hollis examined how algorithmic sensor feedback influences people's emotional self-judgments, in a mixed-methods study with 64 participants (Hollis et al., 2018). "Despite users reporting strategies to test system outputs," according to Hollis and colleagues, "users still deferred to feedback and their perceived emotions were significantly influenced by feedback frames" (Hollis et al., 2018). Some users even "overrode personal judgments, believing the system had access to privileged information about their emotions" (Hollis et al., 2018). Similarly, Lisa Parker and colleagues surveyed the messaging of mental health apps and argued that prominent apps tend to over-medicalize states of distress and may over-emphasize "individual responsibility for mental well-being" (Parker et al., 2018).

As a broad comment, persons with psychosocial disability and the user/survivor/ex-patient movement have – to various degrees – advanced reasons to de-medicalize approaches to supporting people in distress. This reasoning would seemingly extend to caution about framing personal mental crises as medical problems *amenable to digital technological solutions* (see, e.g., Mills & Hilberg, 2020). Nev Jones (2012), for example, has examined the impact of other ways of scientifically framing mental distress, including genetic and neurobiological causal attributions of psychiatric disorder, which she warns is an unduly positivist and can undercut the agency of people in distress, including the nuances of individual experiences. Likewise, the framing effects of biometric monitoring often go unremarked, but the studies noted previously suggest the effects can alienate people from their own self-perceptions. For their part, Hollis and colleagues argue that these framing effects should be acknowledged and, because they are unavoidable, they should be brought out into the open and applied transparently to help individuals more actively construe their personal experiences (Hollis et al., 2018).

Suggesting people can be "alienated from their own self-perceptions" is a risky proposition. Portraying individuals who seek digital forms of support as – crudely put – unreflective dupes very easily perpetuates a view of system "users" as passive and uncritical. Several studies indicate the opposite is true: that people are exerting more agency and critical engagement than may be presumed. Jacinthe Flore's interviews with 14 young adults who used digital mental health apps and wearable devices, for example, suggested that data-driven and automated systems "are not passively experienced" (Flore, 2022). Instead, members of her study group used apps and wearables strategically in ways that suited their individual purposes and in ways not particularly intended by app designers. Similarly, commentators from fields of anthropology and media studies have described the potential for care "to take unexpected forms through technologies, enabling distanced intimacy and social change that transcends the psychology of the individual," to use Hannah Zeavin's terms (Zeavin, 2021). Likewise, Claudia Lang describes the potential for technologies such as chatbots and mental health apps to "weave together code and poetry, emotions and programming, despair and reconciliation, isolation and relatedness in human-techno worlds" (Lang, 2021). Dismissing chatbots as an alienating simulacrum that necessarily deceive their users, or rejecting biometric monitoring techniques as uniformly harmful ways to make humans more amenable to surveillance, control, and exploitation, is clearly going to be simplistic and reductive.

Nevertheless, it seems hard to avoid acknowledging that profiling technologies using biometric data discussed throughout this chapter show quite clear signs of functioning to encourage "the people who are the object of this constant gaze... [to] come to internalize ways of doing things (the government of self), and thereby govern their own conduct" (Paradis-Gagné & Holmes, 2022). This is at least the case regarding the *design aim* of such practices, which are starting to appear in responses to mental health in major governing institutions in society, like education, employment, insurance, and the military (Gooding, 2019). Even if the function of profiling technology in "internalized subjectification" (Stewart & Roy, 2014) is set aside, there is growing evidence to suggest biometric or surveillance technologies, however framed, are disproportionately harming disabled people in precisely these sectors (Brown et al., 2022). Hence, the previously noted concerns raised by Harris, Bossewitch, and others cannot be easily dismissed, particularly as the list of "data harms" in the mental health context grows longer (Bossewitch et al., 2022).

The concern of this group of critics moves beyond questions of how to make particular technologies like biometric monitoring more equitable or ethical (e.g., by ensuring the datasets adequately cover diverse communities that accommodate distinct ways of being and self-presenting). Instead, critics' questions relate to law and political economy, questioning whether technologies are creating a market for surveillance in the mental health context that perpetuates and even extends the worst power imbalances, inequities, and harms of current mental health practices and disability-based rights violations and other objectionable social changes (Harris, 2019; Pasquale, 2019; 2021). Kaitlin Costello and Diana Floegel, for example, argue that the "link between the carceral state and mental healthcare in the United States is alarming" and that biometric monitoring technologies "are poised to only further strengthen that link, despite calls to the contrary" (Costello & Floegel, 2020). More fundamentally, this new ensemble of profiling technology and mental healthcare may well change how it is people can best know the world and the people in it (McQuillan, 2018), including the very nature of what it is to be considered well or unwell.

Moving the Frame from "What Does the Technology Do?" to "Who Is Benefiting and Who Is Not?"

One strategy to avoid the perils of biometric profiling is to place the emphasis away from the technology itself and toward questions of who is benefiting from the push for its adoption and – perhaps more importantly – who is losing (Kak, 2021). This framing challenges the common presentation of computational monitoring and evaluation, particularly in the disability context, as naturally being in people's interests on the basis that "the more we know the more we can help." Such "techno-optimism" or "techno-utopianism" can dovetail easily with widely held understandings about the legitimacy and unquestioned benefit of monitoring disabled people. As Sharon Snyder and David Mitchell have argued, "[o]ne of the primary oppressions experienced by disabled people is that they are marked as perpetually available for all kinds of intrusions, public and private" (Snyder & Mitchell, 2006).

Unsurprisingly, critical reflection has turned to financial incentives and business models associated with biometric data. One such business model is to target individuals with disability-related characteristics with advertising, such as for mental health apps or pharmaceutical drugs (see, e.g., ADHD Drugs 2022), a practice sometimes called "vulnerability-based marketing" (Marks, 2020a; Pasquale & Citron, 2014). In 2017, Facebook operations in Australia, for example, were reportedly targeting children and teenagers as young as 14 years old and helping advertisers to identify when children felt "worthless," "stressed," "anxious," and "insecure" (Levin, 2017). Legal mechanisms proffered to prevent these practices include the GDPR protection of sensitive personal information under Article 9(1), of which vulnerability-based marketing is likely to fall foul. Article 9(1) GDPR prohibits the processing of special categories of personal information, which include health and disability-related data, regardless of its source. The enforceability of such prohibitions remains a problem (Privacy International, 2021), and again, the success or otherwise of these legal approaches remains to be seen.

Beyond businesses trying to sell products, a deeper concern can be raised about the range of beneficiaries who are seeking to promote and entrench the very *explanatory power* of computational ways of knowing the world and the people in it. Jake Goldenfein describes a "particular group of actors that benefits from the idea that measuring and computationally analyzing the world affords access to knowledge – and those actors also have the power to enact and legitimize their knowledge claims" (2020). These epistemological concerns have great significance in the disability context and tie to concerns discussed earlier about both the dominance of certain expert groups in governing responses to disability and the potential intrinsic harms of processes of computational observation and measurement.

Just as the idea of the "medical gaze" (to draw on another Foucauldian term) has helped critique the biomedical and individualistic framing of mental health and disability, and its disciplinary power, the concept of the "data gaze" might be used similarly. The Americans Civil Liberties Union, for example, describes a potential "nightmare scenario" whereby a "data gaze" extends to omnipresent AI-powered monitoring and surveillance:

> the consistent tracking of our every conscious and unconscious behavior that, combined with our innate social self-consciousness, turns us into quivering, neurotic beings living in a psychologically oppressive world in which we're constantly aware that our every smallest move is being charted, measured, and evaluated against the like actions of millions of other people – and then used to judge us in unpredictable ways. (Stanley, 2019)

These concerns were not raised about the mental health or disability context but have clear resonance for this discussion.

Subtle harms can be caused by the way technological surveillance leads to an abstraction of the human body that is then reassembled through a series of data flows (Haggerty & Ericson, 2000; Smith, 2019). Jathan Sadowski has argued that datafication, in which information about the person is commodified, is itself a form of violence (Sadowski, 2020). Jackie Leach Scully and Georgia Van Toorn consider this possibility in the disability context and argue that increasing datafication of the human body, whether in commercial, medical, or governmental contexts, will delineate increasingly rigid boundaries between normality and disability (Scully & Van Toorn, 2021). This impulse to quantify and distinguish embodied difference, they argue, "diverts attention from the realities of disabled lives, at a time when disability scholars and activists are arguing for more rather than less attention to the lived experience of disability" (Scully & Van Toorn, 2021). Goldenfein (2020) proposes the term "computational empiricism" to characterize this impulse toward computational quantification, which is emerging as a knowledge system that presents profiling techniques with the premise that "nonvisible truths reside only in what can be sensed technologically and evaluated statistically."

One clear risk or even function of datafication and computational empiricism is to undermine the need to "act on the reliable narrator" – that is, listening to the person or populations affected and how they articulate their needs (James, 2020). Persons with psychosocial disabilities, mental health service users and survivors, and so on have long campaigned for an end to the type of "epistemic and hermeneutic injustice" that devalues their viewpoint and ways of knowing – individually and collectively – and instead elevates expert-based knowledge claims and systems (see, e.g., McQuillan, 2018; Roper, 2019; Russo & Beresford, 2015; Daya, 2022). Despite these efforts, dominant narratives about technology today often insist on new and alternative ways to undertake expert observation using automated and data-driven systems (Race Based Data 2020). In the mental health and disability context, this insistence creates a greater likelihood of diverting attention from the experienced reality of disabled lives (Scully & Van Toorn, 2021).

A clear step toward responsible governance of automated systems, therefore, is to elevate the often subjugated knowledge of people with disabilities. Deliberative input by affected populations aligns with calls from bioethicists in digital medicine for "interdisciplinary empirical research on the implications of these technologies that centers the experiences and knowledge of those who will be most affected" (Guta et al., 2018). It also aligns with human rights standards to actively involve persons with disabilities in decisions about matters that concern them (CRPD, Preamble 15). Although participatory development of technology in the mental health and disability context may seem axiomatic, it is far from the norm. In 2021, Timothy Kariotis and I reviewed applied studies involving algorithmic and data-driven technologies in "online mental health interventions" on multiple research databases (Gooding & Kariotis, 2021). Of the 132 papers in the survey, only 4 papers (or 3% of the examined field) appeared to involve in any substantive way people with personal experience of mental health services, whether in the design, evaluation, or implementation of the studies. The survey demonstrated "a near-complete exclusion of [mental health service users/patients/disabled people] in the conceptualisation or development of algorithmic and data-driven technologies" and their application to mental health services (Gooding & Kariotis, 2021). This pattern conforms with the longstanding marginalization of the perspectives of persons with experiences of mental health crises and psychosocial disability in academic research, policymaking, and service provision (Brown & Jones, 2012).

Disabled activists and researchers have hit back at exclusion from technological development. Melanie Yergeau's "criptastic hacking," for example, is advanced as a "disability-led movement" for technological tinkering, hacking, and programming that is designed in opposition to "a series of apps and patches and fixes designed by non-disabled people who cannot even be bothered to talk with disabled people" (Yergeau, 2014). Many people living with distress, addiction, disability, and so on have already crafted new technological arrangements (Bossewitch, 2019), pushing back against the treatment of disabled people as passive recipients rather than being treated as knowledge-makers, technologists, mechanics, researchers, and designers. The elevation of disabled perspectives cannot, in and of itself, prevent degrading forms of power or social harms generated by systems of automation and profiling, but it offers a starting point.

Conclusion

The use of technologies like AI to make assumptions and judgments about who we are and who we will become poses greater risks than just an invasion of privacy; it poses an existential threat to human autonomy and the ability to explore, develop, and express our identities. It has clear potential to normalize surveillance in a way that is reminiscent of nineteenth-century asylums as a state-authorized (and often privately run) site of control (Parry-Jones, 2006) but using twenty-first-century techniques of ubiquitous observation and monitoring. Beyond harms to "subject self-formation" and personhood, Salome Viljoen (2021) persuasively warns that attention is also needed to the way datafication materializes "unjust social relations" in ways that enact or amplify social and economic inequality. Discussion about the implications of profiling technologies in the disability context will need to grapple with these individual and collective concerns, for which the CRPD offers a potentially fruitful way to mediate these concerns in international law.

Those with an interest in disability studies, disability rights, and critical mental health scholarship have an important contribution to make to the growing field of research, practice, advocacy, activism, and law reform concerning biometric monitoring. In healthcare, the COVID-19 pandemic has accelerated the international adoption of forms of public health monitoring and security technologies, with similar techniques being adopted quite outside of the care context, including in education, the military, the insurance industry, and the criminal legal system (Kak, 2021). These latter sectors are societal institutions in which people with disabilities, and particularly those with mental health conditions and psychosocial disabilities, face heightened risk of harm. Issues of equality and non-discrimination are (rightly) forming part of the work that is needed to address these harms (see Human Rights Council, 2021). There are strong grounds for expanding this focus beyond ways that particular applications of technology are discriminatory to disabled people, to broader questions about the harmful expressions of power and destructive social and economic changes wrought by computational profiling techniques more generally.

To draw out benefits, and curtail harms, questions that could be explored include whether those deemed through biometric monitoring to be "cognitively impaired" or *likely to become* so will be informed that such attributions have been made. Will they be able to opt out of the monitoring process in the first place? Will they be able to contest such labels before data are transferred to others? Given the purported ease with which personal device data points can be used for automated profiling to determine cognitive impairment, are there sufficient safeguards to govern how this should occur, including whether it should occur in the first place? Will this data and its use be publicly governed as with traditional academic research or retained and governed in the private sector? Should moratoria apply to some forms of biometric monitoring and surveillance in the mental health and disability context on the basis that they are fundamentally harmful or inconsistent with legal instruments like the CRPD? What kind of politics is required for such decisions be made, including arbitrating between trade-offs between collective benefit and certain consequences to specific populations? What role is currently being played by psychiatric and psychological sciences in advancing profiling and biometric monitoring technologies and their regulatory regimes? What role *should* they play?

This is a critical moment to reflect on ways that current choices being made about automation, disability, and care will affect understandings of what it means to be human in the future.

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The Exercise and Enjoyment of Sexual, Reproductive, and Non-reproductive Rights: Gender and Disability Intersectionality

69

Agustina Palacios and Iñaki Regueiro De Giacomi

Contents

Abstract

Based on the rights of autonomy and legal capacity, the article addresses the intersectionality between gender and disability. It includes a focus on both reproductive and non-reproductive rights; namely, the rights to have sex and access to sexual assistance. An overview of the main barriers in the exercise of these rights is also present, including serious human rights violations, such as forced sterilizations. Finally, the authors propose three specific tools under the Convention on the Rights of Persons with Disabilities to prevent infringements of rights: accessibility, accommodations, and support.

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Disability rights · Sexual and reproductive rights, sterilization · Gender rights · Legal capacity · Right to autonomy · Right to have sex · Sexual assistance

Introduction

The International Convention on the Rights of Persons with Disabilities has introduced various standards of international human rights law in personal rights, gender. and disability, which promote and reinforce the values, principles, and freedoms enshrined in international standards.

International human rights law standards have become immensely necessary to address issues such as the “right to have rights” when these are sexual, reproductive, and non-reproductive rights. The case also becomes more complex when those who want to enjoy and exercise these rights are women and even more complicated when these women are women with disabilities (Minieri, 2017).

Discrimination against women with disabilities has a particularly significant impact on their right to sexual and reproductive health. Daily, multiple barriers impede access to information, communication, education, and knowledge, preventing persons with disabilities from fully exercising their sexual, reproductive, and non-reproductive rights. Lack of knowledge, prejudices, myths, and stereotypes often hinder access to contraception and adequate healthcare services. The stereotype of hypersexuality, or on the contrary, the idea that they are asexual and do not feel sexual desire, generally causes women with intellectual and psychosocial disabilities to be conceived as passive subjects referring to their sexuality (Profamilia Project, 2018). In particular, the collective faces innumerable barriers in access to contraceptive information, goods, and services. That, among other issues, prevents them from making autonomous decisions because their consent is based on erroneous or biased information due to stereotypes and prejudices (Minieri, 2017). It is also known that women with disabilities are subjected to forced surgical contraception and abortions without “their” consent – which must be free, informed, and sexuality participative.

Similarly, the loss of autonomy experienced by persons with disabilities not only restricts their ability to express their sexuality according to their sexual orientation but also hinders their recognition in terms of the gender identity that each person identifies with. Therefore, lesbian, gay, bisexual, trans, and intersex persons with disabilities see their rights violated twice, to the extent that any possible association with counter-hegemonic identities is wholly discouraged and made invisible.

Intersectionality as an analytical tool shows that situations of inequality are built from the interaction of various factors of oppression (Barrere Unzueta, 2010). In turn, intersectionality shows that the context and its critical analysis are necessary to understand the oppressed and discriminated against (Serra, 2017). The context comprises several factors of oppression that intersect simultaneously and whose analysis is crucial (CERMI Report, 2017).

Intersectionality as a paradigm works as an interpretative framework, recognizing that the systems of ethnicity, distribution of resources, gender, sexuality, nationality, disability, and age, among others, configure and shape the characteristics of social organizations, which at the same time shape the experiences of oppressed people. In the case of women and girls with disabilities, these characteristics are converted by the systems of power into ableist and sexist stereotypes, which become the two axes of oppression (CERMI Report, 2017).

The UN Committee on the Eradication of Discrimination against Women ("CEDAW Committee") expressed as early as 1991 its concern "...about the situation of disabled women, who suffer from a double discrimination linked to their special living conditions...." They added that "[h]aving considered more than 60 periodic reports of States parties, and having recognised that they provide scarce information on disabled women," their recommendation was "...that States parties provide information on disabled women in their periodic reports, and on measures taken to deal with their particular situation, including special measures to ensure that they have equal access to education and employment, health services and social security, and to ensure that they can participate in all areas of social and cultural life" (CEDAW GR-18, 2008).

Two years later, the UN General Assembly issued the Declaration on the Elimination of Violence against Women and specifically included the concern that "...some groups of women, such as women [...] in institutions or detention, [...and] women with disabilities, [...] are especially vulnerable to violence, ..." (A/RES/48/104, 1993).

In 1999, the CEDAW Committee issued General Recommendation No. 24 in the following terms: "Women with disabilities, of all ages, often have difficulty with physical access to health services. Women with mental disabilities are particularly vulnerable, while there is limited understanding, in general, of the broad range of risks to mental health to which women are disproportionately susceptible as a result of gender discrimination, violence, poverty, armed conflict, dislocation and other forms of social deprivation. States parties should take appropriate measures to ensure that health services are sensitive to the needs of women with disabilities and are respectful of their human rights and dignity" (CEDAW GR-24, 2008).

The CRPD is probably the most essential and representative human rights treaty related to disability rights, but not all human rights were equally considered in the drafting process. Marta Schaaf analyzed in an article how sexual rights were negotiated during the convention's drafting. Comparing the draft presented by the Committee Chair with the text of the Convention as adopted, it is clear that "protectionist measures were maintained and affirmations of sexual rights were eliminated. Discursive silences about disabled sexuality were enshrined in the most important official expression of global disability discourse." The author identifies the Holy See delegation as the main responsible for many of these changes. On the other hand, she concluded that the organizations of persons with disabilities lacked "vigorous advocacy for sexual rights," which probes that they "continue to be reluctant to engage sexuality" (Schaaf, 2011).

Despite this, the treaty includes some relevant provisions. It acknowledges in its article 25 – related to health – the right of persons with disabilities, "...with the same range, quality and standard of free or affordable health care and programs as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes." This specific right includes, for example, the right to receive information in accessible formats regarding available options in sexual support, contraception, and sexually transmitted diseases prevention.

The exercise of sexual, reproductive, and non-reproductive rights by women with disabilities undoubtedly requires a gender and disability perspective.

Although it has not been enough, the gender approach to sexual, reproductive, and non-reproductive rights has been years ahead of disability. It took a process to understand that the right to health, for example, had to include the right to reproductive and sexual health if it was going to protect and guarantee women's health (ICESCR, GC-22, 2016).[1]

However, if the approach starts from the field of disability, the advances are not significant enough. The focus continues today colonized by the medical or psychiatric diagnosis. That is not only a biased vision but also leads to and justifies the restriction, limitation, and/or violation of rights against a group that continues to be considered an object, not a subject (subject of law and, why not, subject of desire).

The social model and the International Convention on the Rights of Persons with Disabilities have provided a change of perspective on disability, to stop conceptualizing it as a limitation of the person. It directly challenges the exclusion of "others," legitimized in our societies through barriers – architectural, communicational, cultural, social, and legal – that prevent the exercise of rights under equal conditions for persons with disabilities (Brogna, 2009).

The exercise of sexual, reproductive, and non-reproductive rights by women with disabilities cannot be addressed if the gender perspective is not included. However, the disability focus should also be included, with a view *from and toward* human rights. The social model from the theoretical framework and the CRPD from the regulatory framework must intersect with the gender perspective based on the principles and values that sustain human rights.

The separation of these two fields (disability and gender) is not innocuous: the consequences can be dramatic and affect mainly the individuals residing in that intersection, such as women with disabilities. In 1988, bioethicists Adrianne Asch[2]

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[1] General Comment 22 on the right to sexual and reproductive health of the Committee on Economic, Social and Cultural Rights establishes that the right to sexual and reproductive health is an integral part of the right to health enshrined in article 12 of the International Covenant on Economic, Social and Cultural Rights (2016).

[2] Adrienne Asch was a scholar who wrote about the intersection of the fields of Bioethics and Disability. She was also a disability studies scholar and a person with a disability. It is important to mention this because sometimes the voices of important experts in the field of disability are considered merely testimonial because of their personal experiences as persons with disabilities and their academic inputs are therefore undervalued. Disability, then, instead of being a necessary

and Michelle Fine used the term “double oppression” to describe the discrimination that women with disabilities suffer twice over (Bergstresser, 2014).

Moreover – and from a political perspective – the sum of both agendas strengthens and enriches each. The forces that push to maintain the current oppression of women and LGBTI people have a lot in common with the ones that subjugate persons with disabilities.

Right to Autonomy

The CRPD provides special protection for autonomy, which is not only protected as a right but also as a guiding principle. Article 3. a refers specifically to “Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons; (...).”

The treaty is based on the idea that autonomy is not so much a starting point as an arrival point, which means recognizing that every person has diversities and limitations. And it is precisely in cases where functional autonomy may be restricted where the role of the right should be highlighted in terms of guaranteeing the full development of the existing degree of autonomy, however minimal it may be.

The CRPD requires ensuring development and promoting autonomy through different guarantees. One of them is the support system established through art. 12. Due to the tremendous philosophical change that this implies, it is the precept that contains the most innovative provision of the Convention, especially concerning certain people who are in a situation of special vulnerability and discrimination when making their own decisions, such as women with intellectual and/or psychosocial disabilities.

Based on recognizing persons with disabilities as moral subjects, another side of autonomy is found in the well-known slogan “nothing about persons with disabilities without persons with disabilities.” This motto is the embodiment of one of the basic principles of the struggle of this movement and the ideology inherent to the social model. This important principle has been forged with a greater focus on the public life of persons with disabilities. This was to prevent decisions regarding policies to be designed and implemented from being taken without the stakeholders’ participation. But also, this principle includes the sphere of private life and the crucial decisions involved in it.

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condition for political legitimacy, becomes some sort of bias of radicalism in the eyes of some individuals without disabilities. Experts with disabilities must be academically valued as experts and politically valued as persons with disabilities. None of these credentials should be conflicting, but appreciated as a whole. “*It was a persistent frustration to Asch that many of her admirers classified her first and foremost as a pioneering voice in clarifying disability rights and tended to overlook or diminish her identity as a Bioethicist. They often based their prioritization on her lifelong blindness, thereby seeming to overlook her training and production in the philosophical analytic basis for work in Bioethics.*”

Legal Capacity

The CRPD replaces the “substitution model in decision-making” with the “support model in decision-making” regarding legal capacity. It imposes the equality clause in legal capacity, guaranteeing the necessary support in situations where people require assistance for decision-making.

This implies prior recognition of legal personality and has significant consequences for the enjoyment and exercise of all rights by persons with disabilities.

Paragraph 2 of article 12 establishes that “persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.” All aspects of life include, obviously, the exercise of sexuality.

This rule, which requires recognizing legal capacity under conditions of equality among persons (men and women, with and without disabilities) in all aspects of life, implies a transcendental change in human rights.[3] Article 12, in particular, generated a Copernican shift in all national civil capacity regulations, which in many countries included a differentiation between the right to hold rights and the right to exercise them.

Both the International Convention for the Elimination of All Forms of Discrimination against Women (Art. 15) and the Convention on the Rights of Persons with Disabilities (Art. 12) thus provide a double anti-discriminatory guarantee, which prevents restricting and/or violating the recognition of the legal personality or the exercise of legal capacity because of gender or disability.

Arlene Kanter describes the change introduced by Article 12 in the following terms: “Instead of paternalistic guardianship laws which substitute a guardian’s decision for the decision of the individual, the CRPD’s supported-decision making model recognises first, that all people have the right to make decisions and choices about their own lives” (Kanter, 2009).

Accordingly, the CRPD Committee interpreted the treaty as requiring all governments to remove the old guardianship system and replace it with supported-decision-making systems (according to article 12.3 CRPD).

Given the implication of legal capacity as a gateway to the enjoyment and exercise of rights, this represented – among many other transcendental issues – the possibility of recognizing and respecting the right to identity, the right to choose with whom to live, where to live, how to live, with whom to build our relationships – among them the right to form a family – the possibility of citizen and democratic participation, and a long etcetera that includes different conditions necessary for the construction of a personal and unique life project (Palacios, 2012). And without a doubt, it provides for the exercise of very personal rights that make up our essence as human beings.

Once the first obligation has been established, which is to recognize that people (women and men) with disabilities have legal capacity on an equal footing with

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[3] The guarantee of equality in legal capacity refers to both the capacity to enjoy or have rights and the capacity to act or exercise them.

others, the second is foreseen, which takes the form of providing measures or support systems for their exercise. Thus, paragraph 3 establishes that *"States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity."*

In this way, the CRPD no longer allows asking *if the person with a disability has* the capacity to exercise their legal capacity but redirects the question to elucidate the person with disabilities' *requirements to exercise their legal capacity.* The response should inquire about accessibility conditions, the adoption of reasonable accommodations, and the provision of a support system. Indeed, all support systems must be tailored to the needs of the person and designed for each case, considering the specific requirements according to their condition and situation.

Recognizing the right on an equal basis with others means that the exercise of legal capacity cannot be limited or restricted due to gender or disability. In other words, to ensure non-discrimination based on gender and/or disability in the exercise of legal capacity, universal accessibility and reasonable accommodation must be guaranteed. This is where the support system comes into play, as part of universal accessibility (if they can be foreseen in advance) and reasonable accommodations if they could not have been expected.

Hand in hand with the abovementioned obligation, paragraph 4 of article 12 establishes the obligation to establish a system of safeguards to prevent abuse in relation to the measures that could be adopted within the support framework. This is vital in the lives of women with disabilities, who suffer abuse and violence to a greater extent than men, and these acts are often committed by those who are supposed to provide support.[4]

Legal capacity is often considered as "the right to have rights" because when a person is deprived of legal capacity (e.g., if she is declared incapacitated), she will not be able to exercise most rights such as voting, getting married, exercising parental responsibility, property management, and so on.

We will refer to the two main obstacles mentioned above from a legal capacity perspective.

Forced interventions: The right to give informed consent to sterilization, contraceptive treatments, and abortion is not legally recognized by people declared incapable or deprived of support systems. A guardian may make this delicate decision by substituting the person's will.

Implicit obstacles to having sex: People declared incapacitated, but also people deprived of support systems or basic levels of autonomy, are generally unaware of

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[4] Paragraph 4 establishes that: "*States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.*"

their rights and live in highly restricted or even closed and incarcerated settings, away from any practical possibility of having intimacy or even social exchanges in general. Therefore, deprivation of sexual life comes from the belief that a person "can't" do anything by herself, which includes having sex, and the person "can't" decide to put into practice her desire, which includes choosing to have consented sexual intercourse. In summary, the legal incapacity framework currently in place in many countries contributes to retaining persons with disabilities without any positivity of sexual exploration or intercourse.

Sexual, Reproductive, and Non-reproductive Rights

Within the personal rights field, the CRPD provides special protection for the right to personal integrity and sexual, reproductive, and non-reproductive rights**.**

Sexual, reproductive, and non-reproductive rights could be defined as "the rights that guarantee free decision on the way of living one's own body in the sexual and reproductive spheres, which implies the right of every person to decide with whom, when and how they have sexual relations or descendants" (Pelaez Narvaez, 2012). Although we know that its scope is much broader, it includes the following (Quan Chang, 2014):

- The right to sexual freedom
- The right to sexual autonomy, integrity, and security
- The right to privacy in sexual matters
- The right to sexual pleasure
- The right to emotional and sexual expression
- The right to gender equality
- The right to make decisions on matters of reproduction
- The right to comprehensive sexuality education
- The right to information based on scientific knowledge
- The right to health in sexual health

Article 25 of the CRPD expressly states that persons with disabilities shall have access to the "same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes."

And more specifically, article 23 establishes the guarantee that "*Persons with disabilities, including children, retain their fertility on an equal basis with others.*"

This aspect of the rights of persons with disabilities has been tabooed and systematically denied throughout history and has a clear gender component. That is, it mainly affects women and girls with disabilities. In this sense, this rule is straightforward. It establishes that non-discrimination based on disability in surgical contraception is genuinely respected, that the person's disability cannot justify this practice, and that it must have the same guarantees as those provided to people without disabilities. This includes the adoption of reasonable accommodations and voluntary support systems.

It is common to require the express and formal consent of the person to exercise personal rights, but an exception is introduced for persons with disabilities. In that case, the consent is substituted by the family, the legal representative, or a judge. Even within the child's rights framework, most current legal systems do not allow legal representatives (mothers/fathers or guardians) to consent to this practice, except in situations of specific and imminent risk to the child's life. However, this is generally allowed for persons with disabilities without the need to demonstrate any risk. These provisions clearly violate the CRPD and the Convention on the Rights of the Child (Fernández, 2016).

A clear illustration of this situation has been the decision of the Colombian Constitutional Court that endorsed in 2014 the sterilization of girls with disabilities without their consent.[5] In this case, the resolution violated the CRPD and the Convention on the Rights of the Child. The Constitutional Court understood that "if the minor does not understand, nor is there the possibility that in the future, he or she will understand the implications of the procedure and the meaning of maternity or paternity, this means that there is a severe or profound level of disability that prevents him from making decisions in this regard and, therefore, he will not be able to exercise his sexual and reproductive rights freely. Therefore, in this case, the request and consent will be signed by the respective legal representative, who must have the interdisciplinary medical certificate confirming the deep and severe degree of disability that prevents the future consent of the minor. The judge will evaluate the preceding in each case and make the decision that best optimises the rights of the minor."[6] It is possible to clarify that sometime later, the same Court modified its position incorporating the standards of international human rights law.[7]

It should also be noted that the CRPD includes essential provisions to guarantee equality in exercising the right to human reproduction. Article 23(1)(b) states that State Parties must ensure that "*the rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognised, and the means necessary to enable them to exercise these rights are provided*."

Finally, the Convention expresses through art. 17 that "Every person with disabilities has a right to respect for their physical and mental integrity on an equal basis with others."

In other words, some specific rights are the following:

- Access to programs for sexual health, reproductive health, and family planning.
- To be free of forced sterilizations and forced contraception.

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[5] Constitutional Court Colombia, Ruling C-131 of 2014.

[6] Constitutional Court Colombia, C-131/2014, no. 6.4.4., para. 2 and 3.

[7] Colombian Constitutional Court, ST-665, Oct. 30/17.

- To have "relationships" broadly (including sexual intercourse).
- To decide if, when, and how often to have children and in which conditions. Similarly, article 16 of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) establishes that men and women have "[t]he same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights."

Right to Have Sex

The very concept of recreational sex dismantles the traditional association between sexual and reproductive rights. In general, they are viewed as an indivisible pairing. But considering sex only as a means of reproduction is problematic in many aspects. First, it encloses a particular moral judgment regarding which uses of sex are permissible or even proper for public or legal debate (e.g., heterosexual coitus of penis and vagina). Also, this association may send a disapproving message to people that cannot or do not want to reproduce. This can significantly affect women, who carry the biologic-centered and deterministic burden of reproduction and childbearing in our society.

In the words of a former UN Special Rapporteur on Violence against Women: "Social pressures, combined with the threat of domestic violence, may result in restrictions on a woman's ability to exercise reproductive and sexual autonomy. A woman's ability to bear children is linked to the continuity of families, clans and social groups. As such, it has been regulated by families, religious institutions and governmental authorities. The importance of procreation to a particular community can pressure women to bear children" (E/CN.4/1999/68/Add.4, 1999).

They are focusing on recreational sex to establish a foundation for freedom. When that right is granted and exercised, many other vital options, such as reproduction, relationships, and love, become available. But without sexual freedom, the range of possibilities shrinks.

Recreational sex is a topic present in the media, literature, and films. Therefore, there is no reason the legal and public debate should exclude it when the subjects belong to a particular group. There is also a longstanding tradition of legal and political concern for forced abortions and sterilizations in the disability agenda, but no such interest in sex as a leisure activity.

It is clear that in some national and international contexts, it is still controversial to mention these issues. That explains their lack of presence in laws, court decisions, and even academia.

For persons with disabilities, the sexual arena is sometimes depicted as a frightening place of rape, abuse, and unwanted pregnancy.

Regarding the CRPD drafting process, Marta Schaaf reflects on this tendency: "Sexuality was mentioned in documents emanating from initial regional consultations almost exclusively in the context of sexual abuse and forced sterilisation; indeed, the sexual vulnerability was presented as a principal area for increased protections" (Schaaf, 2011).

It is rare to find other references to sex rather than abuse in its different forms – no place for mutual consent, no place for pleasure, no place for love. As soon as we change the focus from caregivers' fears to expectations and the right of individuals to engage in sexual activities on an equal basis with others, the situation will change.

To be clear, we are not underestimating the heightened vulnerability of, for example, women with intellectual disabilities to be victims of sexual crimes and sexual exploitation. But the prevention of crimes cannot be the justification of an across-the-board restriction of the fundamental rights of the potential victims.

As stated before, sexual rights are difficult to find, but some milestones exist in international law. For example, the UN Report of the International Conference on Population and Development of Cairo of 1994 defines reproductive health as: "…a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and its functions and processes. Reproductive health, therefore, implies that people can have a satisfying and safe sex life and that they can reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition are the right of men and women to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of birth control which are not against the law, and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant" (A/CONF.171/13/Rev.1, 1994).

It is essential to highlight, in particular, the concept of a "satisfying and safe sex life" as groundbreaking. It was also interesting – and logical – that the document established sexual freedom as a prerequisite for reproductive health. This definition was almost reproduced in the UN Platform for Action of the United Nations Fourth World Conference on Women of Beijing, 1995 (A/CONF.177/20/Rev.1, 1995).

In 1996, Radhika Coomaraswamy, the former United Nations Special Rapporteur on Violence Against Women, wrote in an article about the existence of a movement that was "generating new rights": "The most controversial is the issue of sexual rights, which generally refers to a woman's control over her sexuality and her access to primary and secondary health care and reproductive technologies. It concerns the international recognition of women's rights over their bodies and their sexuality." She described the world conferences of Cairo and Beijing as "a major landmark in this field" (Coomaraswamy, 1996).

Even when the term "sexual rights" was erased from the final version of the Platform of Action, she highlights the sexual autonomy and freedom of choice components (Coomaraswamy, 1996).[8] Coomaraswamy had the opportunity to

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[8] "Though the term 'sexual rights' was included in the draft Platform of Action, it was omitted from the final version, an omission indicating the controversial nature of this suggestion. It must also be noted that the formulation falls short of the right to abortion and sexual preference, an important demand of women's groups and the gay movement. Nonetheless, the inclusion of the paragraph even in this truncated form, and its accompanying vision of sexual autonomy and freedom of choice, are important developments in international human rights discourse."

mention these advancements in her 1999 official UN Report: "[m]any forms of violence against women result in violations of women's reproductive rights because such violence often imperils their reproductive capacities and/or prevents them from exercising reproductive and sexual choices" (E/CN.4/1999/68/Add.4, 1999). We would also like to underline and use the concept of "sexual choices" and "sexual autonomy" cited before.

In sum, we assert that the level of respect for the sexual rights of people with disabilities is minimal. And a cause for this might be social pressures, but not to reproduce. On the contrary, the mandate is to avoid any sexual contact.

Sexual Assistance

Support is a crosscutting concept in the CRPD. It is mentioned regarding legal capacity, employment, education, and so on. The full enjoyment of many rights for persons with disabilities includes the provision by the state of appropriate support tailored to the person's needs. Is sex another field where support should be granted?

Marta Schaaf identifies Tepper and Shuttleworth as authors who consider "the experience of pleasure" as "an accessibility issue" (Schaaf, 2011) for persons with disabilities. But what happens when a third person is involved? Can we still refer to accessibility?

In 2011 the Argentinean disabled persons organization REDI published a report (REDI, 2011) called "El derecho a la autonomía de las personas con discapacidad como instrumento para la participación social" ("People with Disabilities' Right to Autonomy as an instrument of social participation") that analyzes in depth CRPD's Article 19 (Living independently and being included in the community) and its application to the Argentinean context.

The first remarkable point of this publication, and valuable for our analysis, is that sexual accessibility arises when dealing with the right to independent living. Under the section "Los servicios para la vida autónoma" (Services for an Autonomous Life), there is a brief description of the figure of the "sexual assistant":

> Sexual assistance is implemented in some European countries, such as Germany and the Netherlands, with different objectives and scope. It was created to break with the cultural barriers that restrict a full sexual life by persons with a certain disability or with disfigurement. Originally provided by female prostitutes, sexual assistance triggered a strong social debate that found its balance with deepening the debate and establishing certain rules that would allow sexual climax without recurring to practices commonly associated with sex. In other circumstances, where the sexual climax caused by the sexual assistant is prohibited, he or she acts as a facilitator of the sexual meeting between two persons that, because of their disabilities, are limited to making it by their means. The debate surrounding sexual assistance is still open but advances firmly towards guaranteeing sexual practice as a human right. (REDI, 2011)

Another remarkable concept is naming a sexual practice as a human right. The text suggests that the service could be provided as a facilitator for consented sex between two adults and as a sexual service.

It would be important that future research focuses on the perspective of women with disabilities and LGBTI persons with disabilities as recipients of sexual assistance and its gender implications.

Many countries already have sex subrogate services (sometimes called "Medical sex workers"), including the Netherlands, Japan, Denmark, the United Kingdom, and Australia. In some cases, the service is funded by the state.

Independent living seems to be one answer for this and many other disability issues. A satisfying sexual life in incarcerated settings (where privacy is scarce) is challenging to achieve. Likewise, a very protective family environment also seems to be an obstacle because social and sexual lives are generally intertwined.

Another structural obstacle for this and other types of social interactions is, of course, ableism. The last frontier will be surpassed when prejudice against the "disabled" body and mind is replaced by desire.

Barriers

Women with disabilities are subject to different types of discrimination in exercising their personal rights, such as denial of their sexuality, infantilization, humiliation or rejection of their bodies, among other forms of stigmatization of their sexuality or their maternity wishes. This exposes them to various health risks through factors such as the absence of sexual and reproductive health services, the lack of information and accessible sexual education, defective care in pregnancy, childbirth and puerperium, the prevalence of sexually transmitted infections and HIV, and especially, situations of sexual violence (Profamilia Project, 2018).

Undoubtedly, the most significant difficulties that women with disabilities must face to exercise their legal capacity in accordance with the provisions of art. 12 of the CRPD are communication barriers – which could be summarized as the absence of accessibility in the communication process when it comes to expressing desires, needs, and preferences. Other challenges are *attitudinal barriers*, which include, in some cases, legal barriers as a consequence of prejudices and stereotypes; court rulings with legal interpretations based on prejudices and stereotypes; and lack of support and gender perspective, among many others.

Although women with disabilities must face these barriers to exercise their legal capacity, there are two clear areas where international regulations have placed greater emphasis.

The first is property rights. Decades ago, the Convention for the Elimination of all forms of discrimination against Women emphasized anti-discriminatory protection as a consequence of the violations of rights suffered by women in this sphere.[9] This

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[9] As mentioned, the International Convention for the Elimination of all forms of Discrimination against Women has emphasized the protection of the exercise of the legal capacity of women in the field of property rights. The CEDAW recognizes that in civil matters, women have a legal capacity identical to that of men and the same opportunities to exercise that capacity. In particular, states are obliged to grant women equal rights to sign contracts and manage assets and to provide equal treatment at all stages of the proceedings in courts of law and tribunals.

makes sense given its historical context: This is justified given its historical context, as women had their capacity to exercise their rights to manage their property legally restricted.

But CRPD imposes the obligation to adopt all relevant and effective measures to guarantee the right of persons with disabilities, on an equal basis with others, to own and inherit property, control their economic affairs and have access to equal conditions for bank loans, mortgages, and other forms of financial credit, and to ensure that persons with disabilities are not arbitrarily deprived of their property.

In the case of women with disabilities, disability is often considered negatively to justify the impossibility of exercising these rights. This leads to the fact that today women with disabilities continue to be discriminated against "for reasons of disability" in the exercise of their maternity, in self-referential decisions that involve reproduction, in the exercise of their sexuality, in the conformation of their identity, in the right to privacy, and a long etcetera.

Considering the situation above of discrimination, the International Convention on the Rights of Persons with Disabilities has emphasized guaranteeing certain personal rights. Among others, the right to dignity, the right to preservation of identity (art. 3), the right to image (art. 8), and the right to freedom – which includes the right not to suffer exploitation, violence, or abuse (art. 16), the right to physical and mental integrity (art. 17), the right to identity (art. 18), the right to privacy (art. 22), the right to form a family, to exercise their maternity, to maintain their fertility (art. 23), and the right to sexual and reproductive health (art. 25).

But these rights will be mere utopias if the gender and intersectional perspectives are not included, nor is there the exercise of legal capacity and the necessary support measures.

Meanwhile, women with disabilities face legal barriers in those countries where the Law allows them to be substituted in decision-making involving their right to start a family. As well as the Law itself will enable them to be deprived of their liberty without their free and informed consent (reaching that of their representatives). Or they are subjected to medical treatments without their informed consent (resembling that of their representative). Or the Law allows them to be subjected to forced sterilizations (without their free and informed consent, only that of their legal representative is sufficient).[10]

The need for a legislative reform that guarantees non-discrimination against women with disabilities in matters of sexual and reproductive rights has been supported by the United Nations Committee on the Rights of Persons with Disabilities in various Concluding Observations and General Comments.

The Committee on the Rights of Persons with Disabilities addressed this issue at a general level. The General Comment regarding women with disabilities mentioned sexual and reproductive rights, including respect for the home and family (articles 25 and 23 of the CRPD, respectively). It establishes that the lack of accessibility to

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[10] The Recommendations and General Observations of the Committee on the Rights of Persons with Disabilities have systematically emphasized this reality.

information, services, attitudinal barriers, and substitutive systems will contribute to sexual violence against women with intellectual and sensory impairments. It also leads to forced contraception, sterilization, and the denial of parental responsibility for their children (CRPD GC-3, 2016).

It is also worth mentioning the report of the former Special Rapporteur on violence against women. It addresses the absence of sexual information as a violation of women's reproductive health: "Inadequate levels of knowledge about human sexuality and inappropriate or inadequate reproductive health information and services, culturally-imbedded discrimination against women and girls, and limits on women's control over their sexual and reproductive lives all contribute to violations of women's reproductive health." We would also argue that seeing women with disabilities as asexual is culturally embedded discrimination in the words of the Rapporteur.

According to CEDAW's General Recommendation 24, "States parties should also, in particular: [...] (e) Require all health services to be consistent with the human rights of women, including the rights to autonomy, privacy, confidentiality, informed consent and choice"(CEDAW GR-24, 2008). The inclusion of consent and autonomy applied to women with disabilities reinforces the prohibition on forced abortions, forced pregnancies, and forced sterilizations.

The Rapporteur also indicates that "The right to reproductive health implicates the right to sexuality and sexual autonomy. While sexual and reproductive health rights are linked, they are not coterminus. Underscoring the recognition in the Cairo Programme of Action of the right to have a satisfying and safe sex life, paragraph 96 of the Beijing Platform for Action states that, "the human rights of women include the right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence." Sexual rights include the right to information, based upon which one can make informed decisions about sexuality; the rights to dignity, to privacy and to physical, mental and moral integrity in realizing a sexual choice; and the right to the highest standard of sexual health. / Yasmin Tambiah, "Sexuality and human rights," in Margaret Schuler, From Basic Needs to Basic Rights, 1995, p. 37./". UN doc E/CN.4/1999/68/Add.4 Report of the Special Rapporteur on violence against women, its causes and consequences, Ms. Radhika Coomaraswamy, in accordance with Commission on Human Rights resolution 1997/44 Addendum https://documents-dds-ny.un.org/doc/UNDOC/GEN/G99/103/26/PDF/G9910326.pdf? OpenElement.

In other words, sexual freedom does not imply a reproductive intention, but a reproductive intention implies sexual freedom.

A milestone for sexual liberation was the invention of the contraceptive pill. From then on, sexual activities and reproduction go separate ways for many societies. Reproduction is not seen any more as an inevitable destiny but as the result of a decision. And this is true mainly for women because their bodies are necessarily involved. But reproductive decisions need, as a prerequisite, the person can fully exercise their sexual liberty to have the information and practical opportunities. Without freedom, reproduction is mandatory.

Forced Sterilizations

Involuntary sterilization is a two-fold ableist action. On the one hand, it implies the policy of exterminating future generations of persons with disability, also known as eugenics. The U.S. Supreme Court bluntly put it in 1927: "[t]hree generations of imbeciles are enough."[11] On the other hand, sterilizations are a form of regulating the sexuality of women with disabilities. We will refer to the latter.

In the 2011–2014 period, the CRPD Committee reviewed the reports of 13 state parties. Only in four opportunities (30.77%) there is no recommendation in the final official document regarding forced sterilizations. We are dealing with a global policy against persons with disabilities, even when article 23 of the CRPD prohibits it.

The sterilization of persons with disabilities is not only addressed from the framework of the rights mentioned above but also in another area such as the general framework of protection against torture. This has been stated by the UN Rapporteur against Torture when pointing out that "forced sterilisation is an act of violence, a form of social control and a violation of the right not to be subjected to torture and other cruel, inhuman or degrading" (A/HRC/22/53, 2013). But when these practices are carried out on women with disabilities, they usually go unnoticed or are justified and are not considered a form of torture or other cruel, inhuman, or degrading treatment or punishment (A/63/175, 2008). Along the same lines, the former Special Rapporteur on violence against women, its causes, and consequences pointed out that "there is a long history of forced and non-consensual sterilisations of women with disabilities that are socially and even legally accepted" (A/67/227, 2012).

In the inter-American system, the Inter-American Court of Human Rights recognized that "sterilisations disproportionately affect women because they are women and based on the perception of their primary reproductive role and that they are not capable of making responsible decisions about their health." Given the prevalence of the stereotypes mentioned in the previous paragraph, "sterilisation without consent... has had a greater impact on women who are part of groups with greater vulnerability to suffering this violation of human rights,... because of their... disability." (Case IV vs. Bolivia, 2016).

Among several, it is worth highlighting the recommendations of the Committee on Spain. It pointed out its "concern over the fact that persons with disabilities whose legal status is not recognised may be subjected to sterilisation without their consent, freely given and knowingly" (CRPD/C/ESP/CO/1, 2011).

Accordingly, in its Observation on Peru, the Committee expresses its concern "that Technical Standard for family planning No. 536/2005 – MINSA of July 26, 2005, allows, as a contraceptive method, to sterilize 'mentally incompetent' people without their free and informed consent" (CRPD/C/PER/CO/1, 2012).

The same argument was reiterated about China, noting its concern "that both the State party's legislation and its society accept the practice of subjecting women with disabilities to forced sterilisation and abortion without their free and informed consent" (CRPD/C/CHN/CO/1, 2012).

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[11] Buck v. Bell, 274 U.S. at 207.

Jurisprudence: In Re Eve

The Supreme Court of Canada decided in 1986 a leading case regarding a person that requested judicial authorization to perform non-therapeutic and irreversible sterilization over her 24 years old daughter with an intellectual disability (E. Mrs. v. Eve, 1986 2 S.C.R. 388. Can.). One of the purposes of the sterilization was to relieve Eve's mother "... of anxiety about the possibility of Eve's becoming pregnant and of having to care for any child Eve might bear."

Even when the Court assumed that "Eve" was unable to give consent to the procedure, it stated the following: "The grave intrusion on a person's rights and the certain physical damage that ensues from non-therapeutic sterilisation without consent, when compared to the highly questionable advantages that can result from it, have persuaded me that it can never safely be determined that such a procedure is for the benefit of that person. Accordingly, the procedure should never be authorised for non-therapeutic purposes under the parents' patriae jurisdiction."

Between two rights – the right to reproduce and the "fundamental right to choose not to have children" – the Court refused, "at the behest of a third party, to make a choice." It is also remarkable that they set up a standard regarding the burden of proof and the right to independent representation.

The ruling includes references to a report of the Law Reform Commission of Canada that discovered that "there is considerable evidence that non-consensual sterilisation has a significant negative psychological impact on the mentally handicapped." They added that "[i]n a study by Sabagh and Edgerton, it was found that sterilised mentally retarded persons tend to perceive sterilisation as a symbol of reduced or degraded status." ("Sterilization, Working Paper 24 (1979)").

Also, the Court expressly refused to accept the substituted judgment test.[12] On the other hand, the ruling makes it clear that the mother's decision was based at least partially on the fact that she disapproved that Eve had sexual encounters. As the Court points out: "She was attracted, and attractive to men, and Mrs E. feared she might quite possibly and innocently become pregnant." The Court mentions two other precedents where these parents' concerns were equally involved.[13] As mentioned before, the regulation of sexuality is present.

However, the Court declines the authorization because "...there are human rights considerations that should make a court extremely hesitant about attempting to solve a social problem like this by this means." They considered that "our social history [of forced sterilisations of persons with disabilities] clouds our vision and

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[12] "...it is obviously fiction to suggest that a decision so made is that of the mental incompetent, however much the court may try to put itself in her place. What the incompetent would do if she or he could make the choice is simply a matter of speculation."

[13] First case: "In *Matter of Sallmaier*, 378 N.Y.S.2d 989 (1976), the court, basing itself on expert testimony concerning the likelihood of a psychotic reaction to pregnancy, other evidence of psychological and hygienic difficulties, and the patient's proclivity for sexual encounters with men, authorized the sterilization of a severely retarded adult woman."

encourages many to perceive the mentally handicapped as somewhat less than human. This attitude has been aided and abetted by now discredited eugenic theories whose influence was felt in this country and the United States."

Ashley X

In 2006 a United States case identified as "Ashley's treatment" and "Pillow Angel" gained attention in the media after a publication in the Archives of Pediatrics & Adolescent Medicine titled "Attenuating Growth in Children With Profound Developmental Disability. A New Approach to an Old Dilemma" (Gunther & Diekema, 2006)· Ashley is a girl with cerebral palsy subjected to hormone treatment and surgical interventions. The objective of her parents was to avoid her growth to facilitate the caregiving task. The several procedures were authorized by the Ethics Committee of the prestigious Seattle Children's Hospital. In their article, the physicians state that the intervention is "medically feasible and ethically defensible."

But voices of disapproval appeared among scholars (Kittay, 2011) and within the medical community (Bersani et al., 2007). For example, Carole Marcus, MBBCh, from the Children's Hospital of Philadelphia, published in the section "pediatric forum" of a later edition of the journal a reply titled "Only Half the Story." She argues that the article in the journal was misleading by only referring to the hormone treatment, but that in media articles, it was disclosed that the treatment included the removal of breast buds and hysterectomy. She identifies, therefore, an intention in the treatment to "infantilise her and remove any evidence of puberty and maturation." The original authors later replied, "[t]he exclusion of breast bud removal from our discussion should make clear that we do not consider that procedure necessary or routine part of growth attenuation therapy." Dr. Marcus's question lingers in the air: Why was it performed?

One answer may arise when browsing the parent's webpage,[14] where they encourage other parents to access the treatment and share experiences (even when the procedure was later considered illegal). According to the page, one reason for the mastectomy was that "[l]arge breasts could 'sexualise' Ashley towards her caregiver, especially when they are touched while she is being moved or handled." Also, "[a] dditional and incidental benefits to hysterectomy include avoiding any possibility of pregnancy, which to our astonishment does occur to disabled women who are abused." The argument for the elimination of sexual and reproductive elements in her body then resides in the prevention of abuse but also "sexualization."

Other voices of disapproval came from the disability movement. Anne McDonald is also a person with cerebral palsy. She lives in Australia, where she had to file a habeas corpus to be de-institutionalized. But that was possible because she had support and could overcome the communication barrier. In a newspaper article published in Seattle, she affirms that "[t]o equate intelligence with motor skills is as absurd as equating it with height" and asks that "[n]o child should be presumed to

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[14] http://www.pillowangel.org

be profoundly retarded because she can't talk. All children who can't talk should be given access to communication therapy before any judgments are made about their intelligence." She firmly opposes the treatment as "the roster set by the state and accepted by the medical profession."[15]

Also, a disability rights advocacy organization from the State of Washington called Disability Rights Washington (DRW)[16] prepared a document that recommended the following: "Courts also have limited parental authority to consent to other types of medical interventions that are highly invasive and/or irreversible, particularly when the interest of the parent may not be identical to the interest of the child. Thus, the other aspects of the 'Ashley Treatment' – surgical breast bud removal and hormone treatments – should also require independent court evaluation and sanction before being performed on any person with a developmental disability."

The intervention of the judiciary seems to be an adequate safeguard for DRW to prevent this type of case from occurring.

DRW also prepared and posted a brief video regarding this case on the Internet that includes several opinions from persons with disabilities. For example, Joelle Brouner expresses her concern: "I'm not here to say that parents don't have the right to make decisions. But parents don't have the right to do anything they want for their children. Children are their own human selves. They are not just the property of their parents. They are not just extensions of their parents."

On the other hand, Corinna Fale makes the following dramatic statement: "I was furious when I heard this come out on the news. I was extremely angry not only that it happened, but I was angry at the hospital. After this happened, I had a conversation with my mom, that said, if I had known about this when you were younger, I might have thought about doing it to you."

Tools: Accessibility, Accommodations, and Supports

The barriers that persons with disabilities face when exercising their rights are the consequence of a society planned only for a hegemonic person (usually characterized as a male without disabilities). To eliminate these barriers, the CRPD offers some strategies which require incorporating a broad view of human diversity.

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[15] http://www.seattlepi.com/local/opinion/article/The-other-story-from-a-Pillow-Angel-1240555.php

[16] Disability Rights Washington (DRW) *"is a private, non-profit organization that protects the rights of people with disabilities statewide." "A substantial portion of the DRW budget is federally funded."* http://www.disabilityrightswa.org. They carry out innovative and extremely interesting legal activism, for example, "TR v. Quigley" class action lawsuit for intensive in-home mental health services based in the community to avoid criminal and psychiatric institutionalization. DRW is P&A of the State of Washington. "*The Protection and Advocacy (P&A) System and Client Assistance Program (CAP) comprise the nationwide network of congressionally mandated, legally based disability rights agencies. A P&A/CAP agency exists in every U.S. state and territory. There is also a Native American P&A in the four corners region of the Southwest.*" http://www.ndrn.org/about/paacap-network.html. The federal law is called Protection and Advocacy for Individuals with Developmental Disabilities (PADD) 42 USC §§ 15041–15045.

The primary strategy is universal accessibility, which is the condition that guarantees that all people can access and participate. It is a condition for the exercise of every right (Asís Roig et al., 2007).

To achieve this condition of accessibility, there are two complementary strategies: universal design (for all people) and reasonable accommodations.

Universal design consists of conceiving environments, processes, goods, products, services, objects, instruments, devices, or tools from the beginning in such a way that they can be used by all people, with or without disabilities. Through the technique of universal design, the goal is to achieve universal accessibility. It is a means, an instrument, an activity aimed at achieving that end (CRPD, Art. 2).

Reasonable accommodations are those measures designed to adapt the environment to the specific needs of certain people who, for different reasons, find themselves in a special situation that could not have been foreseen through universal design. These measures tend to facilitate participation on equal terms (CRPD, Art. 2).

Taking the above into account, we could say that accessibility would be the situation to which one aspires; universal design is a strategy at a general and prior level to achieve it; and reasonable accommodations is a subsequent strategy at an individual level when universal design is not enough to ensure architectural and communicational accessibility.

The exercise of legal capacity in sexual, reproductive, and non-reproductive rights requires a third strategy to achieve universal accessibility: support systems.

The support model stipulated in the CRPD is based on the premise that the person does not need a "protective" measure that deprives them of exercising their legal capacity. On the contrary, the solution consists of measures aimed at providing the necessary support to enhance legal capacity. This implies creating and/or adapting tools that guarantee accessibility to the exercise of legal capacity, that is, to make decisions on their behalf with the necessary support by their specific needs (i.e., "a tailored suit") (Bulit Goñi, 2008).[17]

These measures, which can be very diverse, can be accepted without being expressly covered in civil legislation. They could also be contemplated in social policies, as well as in sanitary regulations.

Although support systems consist of different arrangements (advice, interpretation, accompaniment, etc.), the critical element of the support model lies in its underlying philosophy, which materializes in the protected legal interests of autonomy and the exercise of the rights of the person. In this way, the judge can establish that for the celebration of certain legal acts, it is required that the support person

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[17] It is also necessary to differentiate between different types of "support." This differentiation must be established firstly in relation to the type of act and secondly in relation to the type of appropriate support figure. In relation to the first, it is necessary to differentiate between transcendental acts for life (marriage, exercise of maternity, surgical operations, sale or purchase of a house, donation) and ordinary acts of common life (daily purchases, going on a trip, subscribe to a sports club). In relation to the second, it is necessary to make different types of support figures available to the person, which adapt to their particular situation.

expresses having assisted the person in understanding the consequences or implications of the act for their life. For other types of acts, it can be determined that the support assists the person in the manifestation of their will or intention based on the use of alternative communication formats and all other information necessary for the conclusion of the legal act.

Independently of its different modalities, all these dimensions must be developed in judicial and administrative processes such as the sanitary setting. In this case, the support becomes part of the universal accessibility that guarantees exercising the right. That is part of the essential content of the right itself.

The Path Forward

Historically, women's consent has been undervalued. For example, when their legal capacity was not even recognized or when the requirement of consent was overlooked in rape cases. In other words, consent is presumed when women are victims of violence. Still, it is disregarded when women want to decide about their lives (legal capacity) and bodies (contraception, abortion, and sex).

An inclusive and substantive equality model requires bearing in mind factual situations of structural inequality, such as those faced daily and in all spheres by persons with disabilities. In terms of sexual and reproductive rights – as in so many other rights – their reality is far from the legal standard. In this matter, the violation of rights often occurs due to preconceptions and stereotypes that sustain the impossibility of exercising sexual rights by persons with disabilities. This results in the substitution of their will or even the lack of exercise of autonomy, which leads to not knowing one's preferences or desires. Since freedom is a learning process, many persons with disabilities are at a clear disadvantage compared to others.

The paradigm shift initiated by the CRPD recognizes, reinforces, and enhances the autonomy of people who, due to their intellectual or psychosocial condition, have historically been deprived of their right to decide on sexual, reproductive, and non-reproductive issues (Iglesias & Palacios, 2019). And this, at the same time, requires the guarantee of a series of preconditions: reasonable accommodations and supports that are essential to the same right. Simply put, if they are not fulfilled, they annul the existence of the right. In these cases, an intersectional perspective requires that the decision-making process in the sanitary field guarantees conditions of accessibility, adoption of reasonable accommodations, and support measures (Iglesias & Palacios, 2019).

To achieve this, it is essential to deepen and strengthen the awareness of those who are part of the health system and have to guarantee this right through dignified treatment and respect for the autonomy of persons with disabilities. This awareness must include – in light of international law standards – the topic of disability from a human rights perspective; as well as specific content on the management and implementation of public policies with a disability perspective from a universal, transversal, and intersectional design; and guaranteeing non-discrimination, autonomy, and participation of persons with disabilities.

Secondly, it is fundamental to develop a genuinely Comprehensive Sexual Education, establishing active policies to promote and strengthen the sexual and reproductive health of the entire population. This also requires training on gender perspective and sexual diversity for teachers and health staff to provide adequate care, support, and follow-up to women who request assistance exercising their rights.

In this training and implementation, awareness must be strengthened once again, so we can achieve a "comprehensive sexual education with a disability perspective," which also includes persons with disabilities as recipients. In other words, a comprehensive, inclusive, broad, and equitable sexual education, from an open and responsible sexual pedagogy involving non-hegemonic human realities (Peirano, 2014).

Finally, the state must work on developing instruments and/or protocols with tools to provide dignified treatment and guarantee the exercise of rights. However, if such instruments do not yet exist – in the meantime and immediately, without practical obstacles or judicialization – every public official has to create and/or adapt tools that guarantee accessibility in decision-making with the necessary supports according to the individual and specific needs. That would represent the suit tailored to needs and potentialities.

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Part XI

Implementing Policy and Law from a Rights Perspective

Implementing Policy and Law from a Rights Perspective: Introduction

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Roberto Lattanzio

Abstract

The Convention on the Rights of Persons with Disabilities (CRPD) offers critical and fundamental guidance to understanding and interpreting international human rights through a disability rights lens. The CRPD is a foundational tool for lawmakers and advocacy groups in advancing disability rights agendas, and in guiding the understanding of rights in a manner meaningful to persons with disabilities. This introduction provides a brief overview of the objectives of this section and of each of the chapters found within it. In this section, we aim to emphasize the foundational role that the CRPD should have in lawmaking and policymaking and in advancing needed reforms. Grounded in examples from various jurisdictions, the chapters in this section aim to offer approaches to advancing disability rights agendas that draw from the CRPD and further the realization of inclusion and equality for persons with disabilities.

The adoption of the *Convention on the Rights of Persons with Disabilities* (CRPD) signaled a global awakening to the recognition of persons with disabilities as rights holders. The CRPD introduced much-needed critical guidance on how international human rights are to be interpreted in order for those rights to be meaningful to persons with disabilities. Developed through a critical disability rights lens, the CRPD is a foundational tool for advancing disability rights agendas for lawmakers and advocacy groups alike. Notwithstanding the importance of the CRPD, its impact on advancing disability rights domestically is the subject of ongoing development and debate, and is particular to each state party that has ratified it. John Peters Humphrey opined that a great challenge for the United Nations “is to devise effective

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machinery for the implementation and enforcement of the human rights which have now been internationally defined and proclaimed" (Humphrey, 1970).

The CRPD requires that states parties report periodically to the Committee on the Rights of Persons with Disabilities on its domestic implementation, and the Optional Protocol to the CRPD offers individual and group-initiated processes to seek redress for rights violations. Nevertheless, for states that have ratified the CRPD, it has had varying degrees of impact and influence on reshaping domestic legislative frameworks. Unquestionably, the full potential of the CRPD to achieve equality and inclusion for persons with disabilities remains unrealized at the domestic level.

Each chapter in this section explores how the CRPD's principles and substantive rights can be implemented effectively in particular domestic contexts. The chapters rely on examples to illustrate the importance of thoroughly understanding and addressing the exclusion and invisibility in law that persons with disabilities have experienced. The history of persons with disabilities as an equity-seeking group of diverse communities is one of persistent exclusion, ableism, and denial of fundamental rights. Laws have too often failed to address these inequalities, harmed rather than benefited disability communities, or ignored persons with disabilities altogether. Thus, the CRPD offers fundamental and significant guidance in addressing this legacy of exclusion, and in furthering a rights-based approach. Through a legal lens, this section explores some key elements of the CRPD's framework and underlying principles that should form the basis of any domestic legislative and policy development, reform, and implementation.

The section begins with a chapter that explores how the fundamental rationale for the CRPD must always be central in any legislative review or drafting exercise. Since persons with disabilities have been, and continue to be, excluded from legislative development and have not benefited from it, future legal reform must involve persons with disabilities and must meaningfully take into account their histories and experiences of exclusion. While there is a complexity that is specific to each domestic legislative framework, the particular history of persons with disabilities in that context must be understood. Using examples from Canada, the chapter demonstrates how attempts to reform law and policy to comply with the CRPD at times fail to create truly inclusive and beneficial change because they do not address the underlying impacts of exclusion and the fundamental guiding principles that frame the CRPD.

The next chapter in the section explores how historically human rights instruments fail to address intersectionality in a meaningful way, and how the CRPD can be an effective instrument to advance the human rights of individuals beyond siloed approaches. The CRPD assists with establishing a responsive approach to the inequality experienced due to intersecting identities and by multiply marginalized individuals. Grounded in Article 6 of the Convention – "Women with disabilities" (CRPD, 2006) – the chapter explores themes of intersectionality and the role of the CRPD in advancing social advocacy movements. The abortion rights campaign in Ireland is provided as a case study.

Institutionalization is a clear example of a discriminatory practice that exemplifies the invisibility of persons with disabilities. Institutionalization deprives people with disabilities of their fundamental rights, and by design completely excludes them from society. With a focus on Article 19 – “Living independently and being included in the community” (CRPD, 2006) – the third chapter in the section offers an analysis of laws that regulate housing, disability services, and supports within the Canadian context. The chapter unpacks the ways in which these legislative schemes miss the mark on accessibility, inclusion, adequacy, and quality of services needed to make independent inclusive living a reality for persons with disabilities.

Lastly, the final chapter in this section explores how the CRPD can provide important legal guidance to reduce vulnerability and address discrimination in disaster response and management. Relying on the CRPD’s principles and Article 11 – “Situations of risk and humanitarian emergencies” (CRPD, 2006) – the chapter offers a critical analysis of disaster theory and disaster management. It examines how the CRPD’s disability rights framework and intersectional approach can be applied to disaster and humanitarian response.

As every legal practitioner can attest, the law is not, and never can be, static. Human rights law in particular has significantly developed and evolved since the adoption of the *Universal Declaration of Human Rights* seventy-five years ago. The CRPD’s influence on disability rights can be just as significant, as it offers the much needed critical lens to make human rights meaningful for disabled people.

Law and policymakers, adjudicators, and advocacy groups all have important roles to play in ensuring the realization of the CRPD’s promise. Strategies to achieve this change will be diverse, as differences in approaches to treaty ratification and differing legal traditions, for example, will dictate particular challenges and barriers to CRPD implementation into domestic law. The great challenge ahead is for each ratifying state to effectively implement CRPD rights in its particular domestic context in a meaningful way. While each state is unique, there is important cross-jurisdictional learning from one another’s experiences. Relying on the CRPD as a compass for change, the intent of the chapters in this section is ultimately to offer approaches and considerations that may have relevance and can be adapted, notwithstanding the differences among domestic legal systems, to further the realization of inclusion and equality for persons with disabilities.

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Law-Making Within a Critical Disability Rights Framework

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Kerri Joffe and Roberto Lattanzio

Contents

Abstract

The *Convention on the Rights of Persons with Disabilities* (CRPD) is a fundamental instrument for interpreting international human rights within a disability context, and an important tool for advancing disability rights agendas. Among states that have ratified the CRPD, it has had varying degrees of impact and influence in advancing and shaping legislative, regulatory and policy frameworks. This chapter explores foundational elements found within the CRPD, which, the authors argue, must guide and shape the review and development of legislation, regulations and policies by States Parties. The Chapter relies on illustrative examples from the Canadian context.

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Introduction

The United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) represents a seismic shift in how international human rights are understood within the context of disability. The CRPD offers a disability-specific rights framework aimed at achieving substantive equality and full inclusion for persons with disabilities. The CRPD is a blueprint of sorts. It invites States Parties to accelerate domestic legislative and policy reforms, and it enables disability communities to advocate for rights-based approaches to laws and policies that affect them. Durham and Quinn explain that, “[t]he Convention radically re-frames disability and accentuates the moral agency of the person, situating people with disabilities not as objects to be managed or pitied, but subjects with equal human rights. States Parties are expected to take proactive measures to sensitize general laws and policies to the situation of persons with disabilities, and these latter are envisaged as partners and co-producers in the process of change” (Durham & Quinn, 2022).

Thus, the CRPD is undoubtedly the most significant international human rights treaty from a disability rights perspective. It provides an understanding of civil, political, economic, social and cultural rights for persons with disabilities and establishes obligations that states must fulfill in order to ensure the full and equal enjoyment of these rights. While new rights per se are not enshrined in the CRPD, the treaty’s disability-specific interpretation of many well-established rights requires significant reform by States Parties in order for those rights to be realized by persons with disabilities.

Fundamental Objectives of the CRPD

Quinn and Degener explain that a driving factor motivating the need for the CRPD was the invisibility of persons with disabilities within existing international human rights frameworks (Quinn & Degener, 2002a, b). While seminal international human rights treaties, such as the *Universal Declaration of Human Rights*, the *International Covenant on Economic, Social and Cultural Rights,* and the *International Covenant on Civil and Political Rights* have always applied to persons with disabilities, these treaties do not articulate core human rights within a critical disability framework. Moreover, in practice, states were not implementing these core human rights in a manner that benefitted persons with disabilities, and the emancipation of persons with disabilities was not treated as a critical human rights issue within the international community (Quinn & Degener, 2002a). Over time, a consensus emerged that a disability-specific human rights convention was needed.

The CRPD aims to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (CRPD, 2006). Each of the substantive articles of the CRPD articulates a particular right or freedom and the corresponding state obligations with a disability perspective. The CRPD articulates the rights and freedoms of existing human rights treaties within the circumstances of disability, "in such a way as to clear a path into the mainstream and create genuinely inclusive and equal societies" (Quinn & Degener, 2002b).

Among the central animating features of the CRPD is the remedying of the ongoing impacts of long-standing, deep-rooted exclusion of persons with disabilities from all aspects of daily life. Quinn and Degener explain that it is the positive spotlight on difference that human rights frameworks seek to uncover. Eugenics is a prime example of how differences in the human condition can be used to devalue and depreciate the exercise of rights based on disability. The authors attribute this compounding and layered depreciation of rights as the product of the "relative" and "absolute invisibility of persons with disabilities." It is thus, the fundamental intent and purpose of the CRPD to address the "invisibility" of persons with disabilities (Quinn & Degener, 2002a).

The spotlighting and remedying of such exclusion by a human rights framework is deeply complex. It requires a deep and meaningful understanding of the unique exclusion experienced by persons with disabilities and intersecting identities. It requires an understanding of the particular experiences of persons with disabilities in the state's context, and the ways in which disability communities have been marginalized, excluded, and made invisible. States must attend to establishing this knowledge. This knowledge must play an important role in the development and the reform of laws, policies and processes aimed at creating just societies that are truly inclusive of persons with disabilities.

Role of the CRPD in Legislative and Policy Development

While there are different approaches by signatory and ratifying States Parties to implementing international treaties such as the CRPD, ratification requires that existing and new legislation and policies align with treaty obligations. Article 4 of the CRPD outlines the general obligations of ratifying governments to ensure that their laws, policies, customs, and practices are reviewed, amended, abolished, and adopted toward the full realization of CRPD rights and freedoms (CRPD, 2006). The CRPD and its Optional Protocol offer numerous processes and mechanisms to monitor and report on this alignment or lack thereof.

These undertakings of States Parties to advance the substantive and fundamental rights in the CRPD are guided by foundational principles enshrined at article 3. Under article 3, legislation and policy must respect the "inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons"; must ensure non-discrimination, full inclusion, a disability-specific understanding and acceptance of difference, substantive equality, accessibility, and respect for the evolving capacities of children with disabilities (CRPD, 2006). The CRPD's substantive articles must be interpreted in a manner that advances these principles. The principles and substantive rights in the CRPD are not to be read in isolation, but rather as inter-connected with one another. As a result, the CRPD must be interpreted and implemented within an intersectional lens, and through cross-disability and multiple disability approaches.

Ensuring that laws and policies comply with the rights and obligations laid out in the CRPD requires States Parties to consider its fundamental objectives. Addressing the deep-rooted exclusion and persistent invisibility of persons with disabilities requires more than just compliance with the letters of each article, but rather a conscious and targeted approach motivated with this intent. Thus, when reviewing and drafting laws and policies, a mere checklist does not suffice. Rather, a careful and meaningful understanding of the unique injustices experienced by persons with disabilities within specific and particular contexts is required. States Parties must deeply reflect on, and understand histories of exclusion, marginalization and eugenics, and the impacts of those legacies, on how persons with disabilities engage with legal rights and obligations within public and private contexts. The CRPD demands a deep understanding and acknowledgement of the core problems at issue, alongside disability communities, in order to identify legislative and policy solutions.

The CRPD is at once both a set of legal obligations that states must abide by, and a broader tool to guide states to actively consider and act to create truly inclusive societies. As a broader tool, the CRPD, its General Comments, and normative works can provide lawmakers and policymakers with a deeper understanding of the impact of exclusion and invisibility experienced by persons with disabilities. This understanding is a critical starting point when developing new legislation and policy; understanding how and why disabled people have been dehumanized, excluded, and made invisible is necessary in order to craft policies and laws that address these experiences. The CRPD, its General Comments, and normative works are also a rich source of legal principles for lawmakers and policymakers to draw upon to develop innovative and truly inclusive policies and laws.

Fundamental Objectives of the CRPD as Critical Guidance in Legislative and Policy Development: Examples from Canada

Canada ratified the CRPD in 2010 and acceded to the CRPD's Optional Protocol in 2018. Even so, people with disabilities in Canada continue to experience discrimination and face a myriad of barriers in most areas of life. In Canada, much work remains to be done to implement the rights and freedoms contained in the CRPD. In each of the examples described below, we consider legislation and policies designed to respond to particular disability-related issues in the Canadian context. We describe some of the ways in which these laws and policies have failed to realize the fundamental objectives of the CRPD. We argue that what is needed is an approach to legislative and policy development grounded in understanding disability communities' experiences of invisibility in a particular context. This understanding is an important starting point for creating laws and policies that comply with the letter and spirit of the CRPD.

Deinstitutionalization and the Unrealized Promise of Article 19 in Ontario

In Canada, the treatment of people labelled with intellectual and developmental disabilities is a stark example of the experiences of invisibility that the CRPD seeks to remedy.

Since at least the 1800s, persons labelled with intellectual or developmental disabilities have been housed, warehoused, and imprisoned in publicly funded large institutions in Canada. In the Canadian province of Ontario, the first large institution for people with intellectual or developmental disabilities opened in 1876 (Brown & Radford, 2015). Institutions were believed to be places where persons with disabilities could go to have their disability "treated," an approach wholly informed by the medical model of disability. Paternalistically, they were thought of as places where disabled people would be protected and well-cared for (Brown & Radford, 2015). In reality, however, institutions were places of systematic control, abuse, cruelty, and degradation (Spagnuolo & Earle, 2017; People First of Canada, 2008). Many people died in institutions, many were abused, and many were forcibly sterilized without their consent (Inclusion Canada et al., 2021; Dolmage v Ontario, 2010).

The public policies, social programs and laws that governed institutions reflected the dominant approach of the era (Whitehead & Hughey, 2004): one where persons labelled with intellectual and developmental disabilities were viewed as different from others, and incapable or not deserving of living in communities or determining the course of their own lives. The presence of large, purpose-built institutions also reflected the sinister view, held by eugenicists, that it was necessary to confine people labelled with intellectual or developmental disabilities in institutions to remove them from society. This served to eliminate the supposed "threat" they posed of contributing to social unrest, deviance, or societal contamination (Brown & Radford, 2015).

In Ontario, the last large, purpose-built institution for people with developmental disabilities closed on March 31, 2009. However, to this day, large, purpose-built institutions continue to operate in other Canadian provinces (Linton & David, 2022; Manitoba 2022; Spagnuolo & Earle, 2017). In addition, in many parts of Canada, people with intellectual or developmental disabilities continue to live or be warehoused in institutional settings such as hospitals, long-term care facilities, psychiatric facilities, and prisons (Linton & David, 2022; Disability Rights Coalition v Nova Scotia (Attorney General), 2021).

From a disability rights perspective, institutionalization is a violation of several core human rights. The UN Committee on the Rights of Persons with Disabilities has explained that institutionalization:

> is a discriminatory practice against persons with disabilities, contrary to article 5 of the Convention. It involves de facto denial of the legal capacity of persons with disabilities, in breach of article 12. It constitutes detention and deprivation of liberty based on impairment, contrary to article 14. States parties should recognize institutionalization as a form of

> violence against persons with disabilities. It exposes persons with disabilities to forced medical intervention with psychotropic medications, such as sedatives, mood stabilizers, electro-convulsive treatment, and conversion therapy, infringing articles 15, 16 and 17. It exposes persons with disabilities to the administration of drugs and other interventions without their free, prior and informed consent, in violation of articles 15 and 25 (Committee on the Rights of Persons with Disabilities, 2022).

In addition, institutionalization violates article 19 of the CRPD, the right of persons with disabilities to live independently and be included in the community (CRPD, 2006).

Animating all of these articles are the human rights principles espoused in article 3 of the CRPD: respect for inherent dignity, autonomy and independence; equality; the freedom to make one's own choices; and full and effective participation and inclusion in society (CRPD, 2006). Indeed, these general principles are the foundation of the right to live independently and be included in the community (Committee on the Rights of Persons with Disabilities, 2017).

Recognizing some of the harms caused by decades of institutionalization, governments have introduced legislative and policy alternatives. For example, in the 1970s, Ontario introduced a framework for the funding and operation of community-based services for people labelled with developmental disabilities (Developmental Services Act, 1990). In 2008, Ontario passed legislation entitled the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* (2008). This legislation was part of a public policy shift away from large, segregating purpose-built institutions and toward a system of services and supports intended to enable people with developmental disabilities to live and participate fully in communities of their choosing. The government responsible for the legislation promised that it would build a modern, fair and sustainable public developmental services system. This system was intended to give people with developmental disabilities and their families more independence, choice and foster their full inclusion in society (Legislative Assembly of Ontario, 2008).

Since the adoption of the 2008 legislation, there have been some positive changes to Ontario's public developmental services system, such as the elimination of large, purpose-built institutions and the funding of person-directed planning to support people with disabilities to create life-plans. With the legislative changes came expanded funding for some people with disabilities and their families to hire their own supports, thereby exercising more choice and control over the services they receive.

However, despite the improvements brought on by legislative reform, many aspects of Ontario's developmental services system continue to be characterized by paternalism, segregation and a charitable approach. For example, the variety of group homes and community-based living arrangements available under the 2008 legislation, may nonetheless perpetuate the hallmarks of large, purpose-built institutions including: their use of physical and chemical restraints; insufficient measures to prevent abuse; isolation from family and community supports; rigid daily routines set by staff regardless of residents' will and preferences; lack of choice or control over day-to-day life decisions; and obligatory sharing of assistants with other residents (Committee on the Rights of Persons with Disabilities, 2017; Ontario Ombudsman, 2016).

Further, the 2008 legislation does not enshrine any rights for people with developmental disabilities when they receive developmental services and supports. The law does require each developmental service provider to create its own rights statement, but does not specify what rights shall be included (Quality Assurance Measures). Without this legal guidance, the practical reality is that the substantive service rights in question vary from one service provider to another. People living in one group home may have fewer or different rights than those living in a group home in another geographic location within the same province. Moreover, some service providers have not created any rights statements at all.

When problems arise in the provision of developmental services, people who receive these services, their families and supporters are often reluctant to complain about rights violations for fear of losing their services, being evicted from their group home, or suffering reprisal for having made a complaint. Losing services or being evicted from a group home is a grave concern as waitlists for alternate placements in group homes, developmental services, and direct funding are incredibly long, often stretching to years (Leroux v Ontario, 2022).

For those who do decide to seek redress, the only way to make a complaint or raise a concern is to the staff or management of the agency or service provider (Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008). There is no independent legal or administrative process for people with disabilities to seek a remedy or access justice when they experience problems related to their developmental services or funding. The government department responsible for administering developmental services does offer a hotline (Ontario, 2022). However, the hotline is limited to receiving reports of abuse and does not receive or act upon other complaints of rights violations (see Appendix, 1.1).

This absence of an independent, accessible accountability mechanism is another example of the paternalism and charitable approach that characterizes Ontario's public developmental services system. Without proper accountability mechanisms, people labelled with intellectual or developmental disabilities who receive developmental services remain passive recipients of government largesse, rather than rights-holders who utilize services and supports that are accountable to them.

Foundational Principles as Critical Guidance in Legislative and Policy Development

The passage of Ontario's 2008 developmental services legislation marked an attempt by law-makers and policy-makers to rectify the injustices of institutionalization, and respond to the needs of persons labelled with developmental disabilities and their families by creating a modern system of community services and supports. This modern system emphasized new funding streams, supports, and administrative mechanisms to determine eligibility for services. Without doubt, more funding, more material supports, and better administration are urgently needed to meet the demand for community-based housing, developmental services, supports, and direct funding. However, more funding and better administration are not the *only* needs. What is also needed is the creation of a system of economic and social supports grounded in the human rights principles of dignity, equality, the freedom to make one's own choices, and full and effective participation and inclusion in society, as articulated in article 3 of the CRPD and underscored as the foundation of article 19, the right to live independently and be included in the community.

An important starting point for creating such a system is to understand the deep-rooted exclusion and persistent invisibility experienced by persons labelled with intellectual and developmental disabilities in Canada. With this understanding, law-makers and policy-makers can then derive laws and policies that respond to the injustices of the past, and create economic and social services and supports aimed at liberating people with intellectual and developmental disabilities so that they can live with dignity in communities of their choosing, guided by the CRPD's principles, and in compliance with article 19 of the CRPD. For example, one of the ways that institutionalization renders people with disabilities invisible is by exerting control over residents' daily life and removing residents' opportunities to make their own decisions. Remedying this invisibility requires systems and supports that recognize the right of persons with disabilities to exercise legal capacity on an equal basis as others; that include the supports necessary for people to exercise this right; and that create opportunities for people to exercise the right by making decisions about where they live, with whom, what daily activities they engage in, and from who they receive supports. As explained by the CRPD Committee, the right to exercise legal capacity is an essential component of the right to live with dignity in the community (Committee on the Rights of Persons with Disabilities, 2017). This approach is very different from an approach focused on administration of funding and service delivery; it includes much broader considerations and requires new, innovative supports to be developed.

Advancing Inclusive Education Within an Exclusionary Framework

The right to education is a core human right, and is central to numerous international instruments including the *Universal Declaration of Human Rights* (art. 26) (Universal Declaration, 1948), the *International Covenant on Economic, Social and Cultural Rights* (art. 13) (ICESCR, 1966), and the *Convention on the Rights of the Child* (Convention on the Rights of the Child, 1989). The *International Covenant on Economic, Social and Cultural Rights* identified the right to education as foundational in ensuring that all people, "participate effectively in a free society, promote understanding, tolerance and friendship among all nations and all racial, ethnic or religious groups, and further the activities of the United Nations for the maintenance of peace." (ICESCR, 1966, art. 13.1).

The CRPD is the first treaty that offers a deeper understanding of what the right to education must entail to advance substantive equality and full citizenship for students with disabilities. Inclusive education, as articulated in article 24 of the CRPD, is the unequivocal expression of the right to education within the context of disability.

In Canada, education law and policy fall under provincial authority. Canada has not developed a national strategy on the implementation of article 24. The province of Ontario's *Education Act* (Education Act, 1990) is a comprehensive statute with many regulatory frameworks in place. Together, the Act and its regulations establish the delivery of public primary and secondary education in Ontario.

In 1980, the Act was amended to address the exclusion of students with disabilities, who did not have a right to a public education (Education Amendment Act, 1980). The framework designed at that time was intended to "integrate" the previously excluded students with disabilities into the public education system. The approach adopted was largely premised on the identification of students with disabilities within a set category of labels and the placement of those students within a range of options from a fully segregated classroom to an integrated placement in a regular classroom. Despite these legislative changes, students with disabilities remained without the right to an inclusive education. In 1997, a seminal decision of the Supreme Court of Canada styled *Eaton v. Brant County Board of Education* found that a student with cerebral palsy did not have a right to a regular class placement in her neighborhood school. While over a quarter of a century has passed since that decision, during which time the CRPD was ratified by Canada, the legal framework in practice remains essentially the same.

Article 24 of the CRPD states unequivocally that students with disabilities have the right to be included in all educational settings. In contrast, Ontario's *Education Act* fails to establish a right to inclusion for students with disabilities. Moreover, there is an evident absence of human rights principles within the *Education Act*'s legislative and regulatory frameworks and practices, as they relate to students with disabilities. Ontario's non-discrimination legislation, the *Human Rights Code* (Human Rights Code, 1990), applies to the delivery of primary and secondary education to students with disabilities. It offers direction and clarity on the procedural and substantive obligations of school authorities to accommodate students with disabilities.

A critical component of the right to inclusive education is the identification and delivery of appropriate, individualized accommodations to students with disabilities within inclusive education settings. The *Education Act* does not wholly incorporate these human rights principles; instead, it relies on its own jargon and approach, emphasizing the identification and labelling of students with disabilities, rather than the provision of individualized disability accommodations.

Under the *Education* Act, much attention is placed, or rather misplaced, on maintaining an artificial separation between "placement" and "services." The Act establishes a clear process for identifying students with particular disabilities and placing them in particular classrooms. It includes a corresponding legal avenue for appealing those decisions in the form of an administrative tribunal dedicated to adjudicating these appeals (Reid et al., 2020). However, the Act does not offer a similar process to determine and deliver the actual accommodations and supports that students with disabilities need in order to ensure that they have equal and meaningful access to education. Rather, the legislative scheme creates an artificial distinction and is essentially silent on the process and substance of disability accommodations and appropriateness of educational programs and services. It is equally silent on conflict resolution and due process regarding these matters. Thus, while a decision to place a student in a particular classroom setting can be challenged through a process that includes an appeal to an administrative tribunal, the nature of the supports or accommodations provided or denied cannot be directly challenged in any formalized process pursuant to the *Education Act* (*Education Act*, s. 57, and see Identification and Placement of Exceptional Pupils). The legislation's failure to offer any structural accountability mechanisms or complaints processes when disability accommodations are insufficient, inappropriate, or non-existent underscores its artificial emphasis on classroom placement, rather than ensuring that students have the supports they need.

As a result of this fractured approach, parents continue to report failures by the education system to appropriately support and accommodate their children. Moreover, parents report that some schools refuse to offer disability-related accommodations until after their student has gone through the process of identification and placement under the *Education Ac*t. This fractured approach fails to consider students as rights holders. It gives education administrators authority to create processes that do not guarantee meaningful and effective participation of students with disabilities (see Appendix, 1.2–1.4).

Moreover, while there are many students with disabilities who are in "fully integrated" educational placements throughout Ontario, inclusive education may be just as elusive for them as it is for students in segregated placements (see Appendix, 1.2).

The issue of equal access to school is a long-standing one among disability communities. Children with disabilities have long been excluded from educational institutions and even now, this remains a pervasive concern (Reid, 2017). In Ontario, the exclusion of students with disabilities from regular classrooms takes many different forms. One example is students with disabilities being removed from school via the use or threat of a particular provision of the *Education Act*, section 265 1(m). This provision allows for a principal to remove a person from school if that person is thought to be "detrimental to the physical or mental well-being of the pupils." The legislation directs an appeal but with no detail, which wholly divests the development of procedure, timelines and other due process rights onto the education providers. Education providers are also responsible for adjudicating such appeals. There is no government oversight or requirement for data gathering regarding the use of this provision. In practice, this provision is used to exclude or threaten to exclude students with disabilities, often on the basis of their disability or disability-related behavior (Reid, 2017) (see Appendix, 1.4). This is a form of segregation and a practice that is utterly irreconcilable with article 24 of the CRPD and its goal of achieving inclusion in education. Rather than excluding students with disabilities, the primary focus of any inclusive education framework is to ensure that supports remain appropriate, and that learning environments meet the needs of all students.

There is no one reason that accounts for the many ways in which students with disabilities are excluded from the benefits of the regular education system in Ontario. Multiple and layered factors including legal, policy, and funding frameworks fail to respond to the needs of students with disabilities. The common denominator is that inclusion is not the stated objective. In its Concluding Observations to Canada's initial report on the implementation of the CRPD, the Committee on the Rights of Persons with Disabilities signaled serious concerns regarding the "persistence of segregated special education environments" for students with high-level support needs, achievement gaps by students with disabilities, and women and girls with disabilities, as well as isolation in particular of "hard-of-hearing and deaf children" (UN Committee on the Rights of Persons with Disabilities, Concluding Observations).

Decades after the initial promise of inclusion into the public education system, Ontario's legislative structure still prioritizes an approach that is designed to fit all students into an old system, rather than placing greater importance on developing a system that provides appropriate and meaningful education to students of all abilities within an inclusive framework.

Foundational Principles as Critical Guidance in Legislative and Policy Development

It is the deeper rooted causes, realities, and impacts of ongoing exclusion in its many forms that inclusive education aims to address. The right to education is the doorway to realizing substantive equality, inclusion and full citizenship for persons with disabilities. Inclusive education can contribute to dismantling barriers that people with disabilities face in accessing housing, entering and remaining in the labor market, attaining social capital, earning income, and gaining appropriate social supports. Article 24 of the CRPD is grounded in the foundational understanding that, "only inclusive education can provide both quality education and social development for persons with disabilities, and a guarantee of universality and non-discrimination in the right to education" (Comment no. 4 at para 2, referencing A/HRC/25/29 and Corr.1, paras. 3 and 68).

Culture shifts, normative and structural, legal and policy changes are all required to bring Ontario's education system into compliance with article 24 of the CRPD. The underlying questions to be asked include what elements of education will lift individuals with disabilities out of poverty, out of unemployment or into labor markets, what are meaningful transitionary practices, what will offer the best possible ways for students to achieve their fullest potential, and ultimately best realize fully inclusive societies.

Article 24 unequivocally articulates inclusive education as the primary mode of education service delivery. It frames students with disabilities as rights holders to be afforded substantive equality in pursuit of achieving their "fullest potential" within all aspects of education. Read in conjunction with the other substantive CRPD articles, article 24 is prescriptive and comprehensive, and is fully understood when interpreted through the prism of the CRPD's article 3 principles. The article 3 principles of substantive equality and non-discrimination, "full and effective participation and inclusion in society," respect for inherent dignity, autonomy and independence, and respect for difference and the evolving capacities of children with disabilities and, "the right of children with disabilities to preserve their identities," take on a very particular meaning when applied to education. These principles inform the need for particular attention to ensure that students with disabilities can participate meaningfully, that they receive individualized disability accommodations, and that school cultures are inclusive. The design of a responsive and appropriate dispute resolution mechanism and due process rights must take into consideration the need for timely resolution and the entirety of the context, needs, strengths and potential of a student.

The *Education Act's* failure to meaningfully address the impacts of segregation and exclusion is also evidenced by the limited and mostly absent opportunities for students to engage directly in identifying the most appropriate supports for them, and the lack of legislative guidance in accommodation planning and implementation.

With its emphasis on identifying students' disabilities and then placing students into a range of educational settings, Ontario's *Education Act* is still in many ways predicated on a "medical model" of disability, which runs counter to the human rights approach and social model understanding of disability espoused in the CRPD. Achieving inclusion is something altogether different from creating processes to determine educational placements, or creating processes to fit students with disabilities into existing structures designed to serve able-bodied paradigms. As the CRPD Committee explains:

> [i]nclusion involves a process of systemic reform embodying changes and modifications in content, teaching methods, approaches, structures and strategies in education to overcome barriers with a vision serving to provide all students of the relevant age range with an equitable and participatory learning experience and the environment that best corresponds to their requirements and preferences. (Committee on the Rights of Persons with Disabilities, 2016 at para 11.)

A responsive approach that is aligned with the CRPD's foundational principles would ensure a legislative and policy framework that centers as its primary objectives each student as a whole, in recognizing their inherent dignity and potential, and corresponding individualized strengths and needs, and a supported inclusive environment to realize those goals.

Ultimately, the CRPD's principles offer needed guidance but also a litmus test of sorts: the way to achieve a fully inclusionary education system is by explicitly rejecting educational philosophies, such as Ontario's, which in one way or another prize segregation over inclusion. Instead, education systems must be designed with inclusion as one of their core objectives.

Accessibility Legislation: An Opportunity for Meaningful Participation in Law-Making

In 2019, the first federal accessibility legislation in Canada, the *Accessible Canada Act*, became law. The purpose of this law is to achieve a barrier-free Canada by 2040 (Accessible Canada Act, 2019). To accomplish this goal, the *Accessible Canada Act* creates a framework for the identification, removal and prevention of barriers to accessibility in specific areas of life that fall within Canada's federal jurisdiction. This includes travel on airlines and railways, broadcasting and telecommunications, federal government employment, programs and services, federal courts and tribunals, Canada's Parliament, and other areas. Organizations, businesses and government departments that fall within federal jurisdiction are required to create plans to identify, remove and prevent barriers in employment; the built environment; information and communication technologies; communication; the procurement of goods, services and facilities; and the design and delivery of programs and services (Accessible Canada Act, 2019). In addition, new accessibility standards will be created, and federal organizations, businesses and government departments are encouraged to follow those standards.

The preamble to the *Accessible Canada Act* recognizes that this legislation is intended to further the "economic, social and civic participation of all persons in Canada, regardless of their disabilities," complementing the rights of persons with disabilities articulated in both domestic and international law (Accessible Canada Act, 2019). In addition, the preamble acknowledges that the legislation plays a crucial role in implementing those parts of the CRPD that require states "to take appropriate measures respecting accessibility and to develop and monitor minimum accessibility standards" (Accessible Canada Act, 2019).

When the *Accessible Canada Act* first became law, there was much excitement and enthusiasm within disability communities across Canada. The legislation created new opportunities to raise awareness about the importance of accessibility and gain meaningful improvements toward more inclusive work, transportation, employment, services and communications in Canada's federal sphere.

Another opportunity engendered by the passage of the new legislation was a chance to create more meaningful and accessible ways for persons with disabilities to participate in the development of new legislation and regulations. Indeed, one of the principles of the *Accessible Canada Act* itself is that "persons with disabilities must be involved in the development and design of laws, policies, programs, services and structures" (Accessible Canada Act, 2019). This is consistent with the core principles of the CRPD, which include full and effective participation of persons with disabilities in society (CRPD, 2006). It is also consistent with the general obligations of States Parties to the CRPD to closely consult and actively involve persons with disabilities (CRPD, 2006).

The Committee on the Rights of Persons with Disabilities has recognized that often persons with disabilities are not consulted about matters affecting their lives, and that decisions continue to be made on their behalf. The Committee has stated that, "Persons with disabilities still face significant attitudinal, physical, legal, economic, social and communication barriers to participate in public life" (Committee on the Rights of Persons with Disabilities, 2018). In response to this experience of invisibility in public life, disability rights movements have demanded not only recognition of their human rights, but also an active role in determining those rights.

Meaningful participation of people with disabilities in the development of laws, policies and programs is critically important for achieving full inclusion. Creating opportunities for such participation is an important way in which states can address the experience of invisibility in public life that has impacted many disability communities. Participating in the development of laws, policies and programs allows persons with disabilities to frame policy issues, to challenge discriminatory and inaccurate assumptions, and to develop an empowering relationship with the law (Löve et al., 2017a, b). It facilitates the building of capacity within disability communities to share their experiences of disability-related barriers and to engage in public issues that affect them (Committee on the Rights of Persons with Disabilities, 2018). Participating in the development of laws, policies, and programs is consistent with a human rights-based approach to public decision-making and helps to ensure good governance and social accountability (Committee on the Rights of Persons with Disabilities, 2018).

In Canada, existing processes to develop new legislation and regulations require governments to consult with the public, including persons with disabilities (Treasury Board of Canada Secretariat, 2018). However, these consultation processes contain many barriers that prevent disabled people from participating. For example, many consultations are held online only and participants are required to submit their input in writing within fairly short deadlines. People with disabilities encounter barriers because online information is in inaccessible electronic formats, because they don't have access to computers or high-speed internet, because they cannot meet the imposed deadlines, or because background information about the consultation is in inaccessible technical terms (ARCH Disability Law Centre, 2021). People with disabilities report being reluctant to participate in legislative and regulatory consultations because their concerns are not listened to, or their input does not have any impact on the final legislation or regulation that the government develops (ARCH Disability Law Centre, 2021). Consultation processes that are inaccessible or not meaningful serve to perpetuate the exclusion of persons with disabilities from participation in public life.

Foundational Principles as Critical Guidance in Legislative and Policy Development

Reforming Canada's existing legislative and regulatory development processes to allow for people with disabilities to participate equally and meaningfully is one important way in which Canada can realize the objectives of the *Accessible Canada Act* and the CRPD. The *Accessible Canada Act*'s principle that "persons with disabilities must be involved in the development and design of laws, policies, programs, services and structures" must be interpreted in accordance with the principles in the CRPD.

Two of the CRPD's article 3 principles, accessibility and full and effective participation in society, are particularly relevant to consider when deciding what reforms to undertake. Applying the principle of accessibility requires that legislative and regulatory consultation processes must be designed to be fully accessible from the outset. This includes, for example, holding consultations at accessible physical and online venues; ensuring that sign language interpreters, communication intermediaries, support persons, attendants and others are provided at consultation meetings; providing participants with background and follow up information in accessible formats and accessible languages; and building in flexibility so that deadlines can be extended as needed (ARCH Disability Law Centre, 2021). Applying the principle of full and effective participation in society requires that consultation processes are not one-time events that have no impact on the outcome of the legislation or regulation. Instead, consultations must allow for meaningful participation. This includes, for example, an ongoing, transparent dialogue between disability communities and governments. Governments must engage people with disabilities early in the legislative or regulatory development process, and there must be opportunities for consultations to have a real impact on the final legislation or regulation (ARCH Disability Law Centre, 2021).

Reforming existing legislative and policy development processes to make them more participatory, accessible and meaningful for persons with disabilities is a significant step that governments can take to respond to disability communities' collective experiences of invisibility in public life. The CRPD's foundational principles and normative works (for example, General Comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention) are resources that states can draw upon to guide such reform. In Canada, such reform is not only mandated by Canada's ratification of the CRPD, but also by domestic legislation.

Conclusion

Degener and Quinn posit that one of the fundamental objectives of the *Convention* is to address the "invisibility" of persons with disabilities. In this chapter, we have argued that addressing the deep-rooted exclusion and persistent invisibility of persons with disabilities requires more than just compliance with the strict requirements of each of the CRPD's substantive articles. Rather, when states develop or review laws, regulations, policies, and programs, these processes must include a careful and meaningful understanding of the unique experiences of persons with disabilities within specific and particular contexts. Understanding how persons with disabilities have been excluded from society is an important starting point for developing laws and policies that respond to these injustices and that realize the fundamental objectives of the CRPD.

The general principles of the CRPD, set out at article 3, provide a critical starting point when developing or reviewing laws and policies. The Canadian examples presented in this chapter illustrate the important role that these general principles can play in legislative and policy development. We have argued, for example, that reforming public services for people labelled with intellectual disabilities requires more than additional funding and administrative improvements; it requires designing a system of economic and social supports grounded in the CRPD's human rights principles of dignity, equality, the freedom to make one's own choices, and to achieve full and effective participation and inclusion in society. Similarly, creating inclusive education services requires designing a system that is inclusive from the outset, guided by the CRPD's principles of respect for difference, equality, dignity, and accessibility. The final example, Canada's accessibility legislation, illustrates how the CRPD principles provide both general impetus and pragmatic direction for reforming legislative and regulatory development processes to make them more accessible, inclusive, and meaningful for disabled people.

While the examples cross different areas of life, common to them are the complex interactions that persons with disabilities continue to have with legislative and policy frameworks that fail to respond to their collective experiences of exclusion and invisibility. The CRPD's principles, foundational objectives, and substantive rights provide tools to guide and shape the review and development of legislation, regulations, and policies by States Parties, offering the promise of addressing the legacies of invisibility.

Appendix

1.1	It is important to note that Canada, and all its provinces and territories, including Ontario, have anti-discrimination laws which protect against discrimination on the basis of disability. If a person believes they have been discriminated against when they receive developmental services, they can initiate a human rights complaint at an independent tribunal charged with adjudicating discrimination complaints. However, in law and in practice anti-discrimination laws do not address the particular legal issues or rights violations commonly experienced by people who receive developmental services. Therefore, the availability of human rights complaint mechanisms does not alleviate the need for an independent, accessible process to adjudicate complaints related to the provision of developmental services and supports.
1.2	Research conducted in Ontario which included results of a survey and interviews, noted that 68% of parents of students with disabilities reported that schools were meeting half or less than half of their child's academic needs, 53% reported improper academic accommodations; 67% reported not receiving the appropriate curriculum; and 61% reported their child was excluded from extra-curricular activities. (Reid et al., 2018)
1.3	Students with disabilities who are racialized and/or identify within a lower socio-economic status experience much higher rates of segregation than other students. A report released by Canada's largest school board stated that "[s]tudents who self-identified as Black were over-represented in congregated Special Education. . .[and] notably under-represented in Gifted, IB, AP, Elite Athlete, and slightly under-represented in French Immersion" (see Toronto District School Board, "Facts, Selected In-School Programs: An Overview," Issue 8, December 2013 (TDSB) at 3).
1.4	Approximately 45% of respondent parents stated that they needed to keep their child home from school as a result of a lack of supports or services. Moreover, more than half of parents reported that their child's day had been shortened, often for reasons not related to the student's needs, such as staffing shortages and transportation scheduling issues. On average, these students lost 3.86 h out of a 6 h school day.(Reid et al., 2018)

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Article 6: How Human Rights Instruments Can Support Movements and Build Bridges

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Maria Ni Fhlatharta

Contents

Abstract

One of the pressing questions of current times is how international human rights instruments can achieve true equality for groups who are multiply marginalized.

The majority of disabled people experience at least one additional form of marginalization – be that based on sexual orientation, gender identity, sexual characteristics; based on race, ethnicity, or migration status; or based on class, economic status, age, or other factors. Meeting the needs of these populations can be challenging, particularly given that human rights instruments are often siloed and focused on a specific issue or group. Some treaties have inserted provisions in

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The term organizations of women with disabilities is used throughout this chapter and is used in a broad way to describe organizations of persons with disabilities that have feminist goals

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recognition of specific forms of multiple marginalization, in order that rights of specific groups are not overlooked.

One example is that of Article 6 of United Nations *Convention on the Rights of Persons with Disabilities*, which acknowledges the rights of women and girls with disabilities, alongside the convention including gender equality as a guiding principle in order to ensure the rights of women and girls with disabilities are not overlooked. This was fought for and pushed through by feminist disability rights activists during the negotiation of the convention. While this is only one group of multiply marginalized persons, it does provide a template for how human rights instruments can meet the needs of specific groups.

Beyond the question of how rights instruments can address these intersections, is how these rights can be realized for specific groups. For much of the world, a state committing to and ratifying a convention in and of itself does not guarantee the full realization of rights. The domestic implementation of these rights relies on advocacy within the state, and the development and proliferation of social movements in order to achieve change.

While rights instruments struggle to meet the needs of populations, the social movements which advocate for the rights of specific groups or on specific issues are often similarly siloed. This is true of feminist advocacy and disability advocacy. The CRPD Article 6, and related provisions, provides a common language with which to build a bridge between these movements. It also provides a framework to address what are often seen to be conflicts between the disability rights movement and the feminist movement.

We also see the expansion of feminist organizations of persons with disabilities such as Article Six in Poland, Disabled Women Ireland on the island of Ireland, the Indonesian, sisters of Frieda in England, network of women with the development and expansion of these groups, is a significant shift in the disability rights movement.

This chapter will examine how the acknowledgment of intersecting forms of marginalization can support social change movements with a specific focus on UN CRPD.

Introduction

One of the pressing questions of current times is how international human rights instruments can achieve true equality for groups who are multiply marginalized. The majority of disabled people experience at least one additional form of marginalization – be that based on sexual orientation, gender identity, sexual characteristics, based on race, ethnicity or migration status, or based on class, economic status, age or other factors. One in eight people in the world are disabled women – disabled women may also be a racial minority, pregnant, of divergent sexual expression or gender identity, be older, be younger, practice a non-dominant religion, be a migrant, a refugee, or be seeking asylum. Their experiences of marginalization are often not captured through disability-specific concepts of rights. These forms of multiple discrimination present a challenge for human rights law and the disability rights movement.

What Is Intersectionality?

Multiple marginalization refers to a person experiencing marginalization based on more than a single characteristic or ground; intersectional discrimination refers to a situation where several grounds interact with each other at the same and are unextractable. Grounds include age, disability, ethnic, indigenous, national or social origin, gender identity, political or other opinion, race, refugee, migrant or asylum seeker status, religion, sex and sexual orientation, which interact with each other and overlap.

The concept of multiple marginalization or intersectional discrimination can be traced back through generations of black women activists, including during the anti-slavery movement, the civil rights movement, and the early feminist movement (Atrey, 2019). Academically, it was Crenshaw who first used "intersectionality," a term to address how the inequalities faced by black women were poorly recognized and ill served by both feminist and anti-racist movements (Crenshaw, 1989). Crenshaw argued the intersection of gender and race, which needed to be considered to grasp with the complex experience of black women.

At a domestic level, the idea of intersectionality presents a direct challenge to normative constructions of anti-discrimination law – this is well established and illustrated through the cases examined by Crenshaw herself – Crenshaw focused on a number of cases where, while black women were treated unfairly, the courts failed to recognize the discrimination faced.

DeGraffenreid v. General Motors, for example, involved the claim of five black women who had been let go due to a seniority policy. The company had failed to hire black women prior to 1964, which resulted in all of the black women hired by the company in that time being let go during a round of redundancies. Although only black women had experienced disadvantage, the court did not accept this, as to allow for the case to succeed would allow for a special class to be created. Crenshaw used this example, along with other court cases to show how normative concepts of discrimination failed black women.

Intersectionality is the product of the work of black women activists and academics specifically on the struggle faced by black women – but it has been taken to heart by movements of multiply marginalized people the world over – as Atrey notes from #RhodesMustFall to #MeToo – intersectionality is a dominant theme in global justice movements. Intersectionality originally developed by a legal theorist has transcended the walls of the university and beyond in the community it was initially to serve to become a framework through which marginalized persons everywhere could understand and seek to change these systems of oppression (Atrey & Dunne, 2020).

Multiple Marginalization and International Human Rights Law

While discrimination law at a domestic level has often been the focus of discussions on intersectionality, less attention has been given to international human rights law (Atrey & Dunne, 2020).

Human rights have often developed in silos, the early core human rights instruments focused on broad declarations of rights (e.g., The Universal Declaration of Human Rights, International Covenant on Civil and Political Rights, International Covenant on Economic, Social, and Cultural Rights), followed by a specific focus on groups who traditionally experience more rights violations including racial minorities, women and girls, children, migrant workers (International Convention on the Elimination of All Forms of Racial Discrimination, Convention on the Elimination of All Forms of Discrimination Against Women, Convention on the Rights of the Child, International Convention on the Protection of the Rights of Migrant Workers and Members of Their Families). There are also conventions on specific issues such as torture, and enforced disappearances (Convention Against Torture and Other Cruel, Inhumane or Degrading Treatment and Punishment, International Convention for the Protection of All Persons From Enforced Disappearances).

To paraphrase the UN Committee on the Rights of Persons with Disabilities member Sir Robert Martin, we required more human rights instruments because we had a very narrow idea of who was human – we needed to make sure that women and LGBT people, disabled people, Indigenous people, and a lot of different other people all got to enjoy the same rights as everyone else. Human rights are considered rights possessed by all human beings simply in virtue of their humanity. As Atrey notes, rights are guaranteed not just to all human beings but to all human beings equally.

Disability in International Human Rights Law

The *Convention on the Rights of Persons with Disabilities* (Convention and CRPD) disability convention is often said to have come from the invisibility of disabled people. In the 1970s, the United Nations adopted "declarations" on the rights of "mentally retarded persons" and "disabled persons" (1975), but they were limited in scope, non-binding, and adhered to traditional medical model idea of disability. From before the turn of the last century, there were consistent and growing calls for the development of an international disability treaty. In 1999, the Organization of American States adopted the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities, which was the first international treaty on disability discrimination. This was a turning point in the disability rights movement – a stand-alone international treaty on disability rights.

Further challenges remained in order to negotiate a global treaty on disability.

Nothing about Us Without us – the credo for the movement in negotiating the Convention – but it is also quite clear who was at the table when it came to the negotiation. In many respects, the Convention was the most inclusive convention ever developed. The inclusion of the disability community in the development of the treaty is considered a landmark in the history of human rights.

The extent to which other oppressed groups had been involved in the negotiation of their own convention is limited – conventions traditionally being drafted for a group does not include that group. As Series notes, those who experienced the violations of human rights that lead to the early human rights conventions were not for the most part involved in its drafting. It is well noted by actors within the UN system and academics that the CRPD displayed the greatest involvement of civil society in any treaty negotiation, which was unique. It does raise, however, the question about who was not at the table, and of those who were, what voices were loudest.

Recognition of Multiple Marginalization in UNCRPD

For the most part, CRPD follows the form of previous convention attempts at recognizing multiple marginalization. Within the Convention, most forms of multiple marginalization are referenced only within the preamble which states;

"*Concerned* about the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, color, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status." While attempts to expand and strengthen these protections are found within the jurisprudence of the committee, this is a rather flippant acknowledgment. The preamble of the Convention is the longest preamble in any international human rights law treaty, making up about a third of the entire document (Kayess & French, 2008). It is instrumental in establishing the purpose and philosophy as well as capturing the intent of the drafters of the convention. It is by no means to diminish the importance of the preamble to suggest that this acknowledgement belongs somewhere else as well. The preamble is either within the guiding principles or through provisions within the operative provisions of the convention. The invisibility of disability in human rights called out by the disability community in the lead up to the development of the convention is echoed in the invisibility of those whose rights are not fully acknowledged in the convention.

The CRPD is often cited as a challenge to the siloed construction of rights, as it engages with multiple marginalization.

While attempts have been made to ensure that the Convention recognizes multiple marginalization for those from SOGISEC communities, the protections here are arguably insufficient for racial minorities, Indigenous communities, economically deprived, or from linguistic minorities (other than sign language).

The success of recognizing multiple marginalization is most pronounced in terms of gender and disability, where there is both a specific and mainstream recognition.

Youth remains its own distinct challenge, and in particular, how decision-making rights of children can be recognized.

The Convention acknowledges the rights of women and girls with disabilities, alongside gender equality as a guiding principle in order to ensure the rights of women and girls with disabilities are not overlooked. This was fought for and pushed through by feminist disability rights activists during the negotiation of the Convention.

This intersectional interpretation of the Convention has also been emphasized by the committee, most notably in the general comments on Article 5 and Article 6, which take a nuanced approach (Atrey & Dunne, 2020).

The concept of intersectional discrimination recognizes that individuals do not experience discrimination as members of a homogenous group but, rather, as individuals with multidimensional layers of identities, statuses, and life circumstances. It acknowledges the lived realities and experiences of heightened disadvantage of individuals caused by multiple and intersecting forms of discrimination, which requires targeted measures to be taken with respect to disaggregated data collection, consultation, policymaking, the enforceability of non-discrimination policies, and the provision of effective remedies.

Reproductive Rights Within the CRPD

The issue of reproductive rights is one that disproportionately impacts communities which experience multiple forms of marginalization in particular women and gender minorities who have the capacity to become pregnant. Separate from the broad gender provisions laid out under the CRPD, existing two specific provisions focused on reproductive rights. This is in addition to the non-discrimination protections under Article 5, which would apply to the area of reproductive health.

Article 23 states:

> b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided.
>
> c) Persons with disabilities, including children, retain their fertility on an equal basis with others.

Article 25 states that States Parties must "[p]rovide persons with disabilities with the same range, quality and standard of free or affordable health care and programmed as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmed."

During the ninth session on the committee on the convention on the rights of persons with disabilities, the committee held 1/2 day of general discussion focused on women and girls with disabilities with a range of topics discussed in terms of human, sexual, and reproductive health rights were identified as the main three issues of concern for this group (Mykitiuk & Chadha, 2018).

A note must be made here on the conflict of rights. In many respects, conflicts within human rights are often false paradigms that are artificially created in a response to a broad restriction of rights. This is often raised in relation to abortion where eugenics is conflated with the right to bodily autonomy. In the concluding observations for the United Kingdom of Great Britain and Northern Ireland, the CRPD committee noted that the state needed to amend its laws to end the discriminatory provisions, which existed in relation to disability, but did not call for restricting reproductive rights further.

We must be clear that reproductive rights are as disability rights issues, and this is clearly articulated in the text of the convention, but also in its interpretation by the committee through general comments, the reporting process, and engagement with the convention on the elimination of discrimination against women.

> Access to safe and legal abortion, as well as related services and information are essential aspects of women's reproductive health and a prerequisite for safeguarding their human rights to life, health, equality before the law and equal protection of the law, non-discrimination, information, privacy, bodily integrity and freedom from torture and ill treatment.

How Does International Human Rights Law Support Social Movements

As conversations about disability justice and reproductive justice evolve, questions arise over to what extent, if any, rights serve disabled people. States purport to take their obligations under international law seriously, and to respect it, but an analysis of reporting to treaty oversight bodies shows that states rarely meet their treaty obligations.

As noted by Hathaway, states which ratify conventions do not actually translate to practice on the ground. Repeated studies have shown that the ratification of human rights treaties does not directly improve respect for human rights at the domestic level. The ratification of such treaties does present a unique opportunity to advance human rights goals. Earlier in this chapter, I described the importance and influence of civil society and disabled persons organizations in the development and the UN signing of the CRPD. While this was groundbreaking, it may describe the secondary role of civil society and "disabled peoples organizations" within international human rights. I would argue that, as if not more vitally, human rights require civil society to engage at a domestic level. While ratification alone does not create social change, research shows the potential for civil society to leverage human rights obligations, and the language of state commitments in order to pressure governments to take action. Social movements themselves have been seen to be de facto enforcement of mechanisms and lead to improved local practices.

For much of the world, a state committing to and ratifying a convention in and of itself does not guarantee the full realization of rights. The domestic implementation of these rights relies on advocacy within the state, and the development and proliferation of social movements in order to achieve change.

International human rights law allows local movements to focus their goals as part of a global struggle. Article describes how framing it as part of a global struggle allows for social movements to gain supporters and material resources. The enforcement itself requires documentation of human rights abuses, which are useful at both international courts and treaty oversight mechanisms, and to issue formal complaints against the states in which they exist.

This symbiotic relationship where local organizations support the development and implementation of international human rights law and international human rights mechanisms provide frameworks legitimacy and guidance to those working on a domestic level, which is crucial to the success of human rights.

While rights instruments struggle to meet the needs of populations, the social movements which advocate for the rights of specific groups or on specific issues are often similarly siloed. This is true of feminist advocacy and disability advocacy. The CRPD Article 6, and related provisions, provides a common language with which to build a bridge between these movements. It also provides a framework to address what are often seen to be conflicts between the disability rights movement and the feminist movement.

An interesting case study on this intersection is that of the abortion referendum in Ireland in 2018. This impacts in turn the use of the Convention by activists campaigning for human rights on the ground. Activism is often fleeting and lacks records, but the use of online space by disabled activists within the Irish Abortion Rights Campaign allows us to track and examine the conversations that were happening within the disability community and beyond.

Abortion Campaign

The Irish Abortion rights campaign spans several decades, but the modern campaign to repeal the eighth amendment is probably best positioned at the 2012 March for Choice, which was the first national march for abortion rights in many years. Several months later, activists were galvanized by the death of Savita Hallapananver, who died due to a failure to provide medical care while she was experiencing a miscarriage. This is often cited as the turning point that led to the repeal of Ireland's constitutional protection of the unborn and strict prohibition on abortion in 2018. From early on in the campaign, disability was used by anti-abortion activists in an attempt to discredit and reject any attempts at reform. This is partially as the constitutional prohibition had been challenged a number of times in occasions where their fetus had been diagnosed with a fatal fetal abnormality. These are instances where the fetus would not survive outside the womb and the pregnancy was non-viable. This was then conflated with disability selective abortion in an attempt to avoid even the most marginal abortion law reform.

The position of disabled people in the campaign was an interesting one. From the outset, disabled people were defined by their absence rather than their presence, but the response to this from disabled women and non-binary feminists was such as to deepen the disability rights movement in Ireland.

Ireland has a long and interesting history of disability rights activism, but feminist disability activism has mostly focused around small collectives and specific activists. At the outset of the modern campaign to reform Ireland's abortion law, no specific feminist disabled persons organization existed at the outset of the campaign, nor were there many disabled persons organizations in existence at the time.[1]

Many disabled feminist activists spoke loudly from the outset of the modern era of the abortion movement in Ireland about the need to include. Noted disabled feminist and academic Rosaleen McDonagh wrote in an opinion piece in 2013, a year after the first modern March for Choice; "Anti-abortion pontificators, using disability as a calling card for their agenda, is disturbing and frightening. Patronizing ideologies about people with disabilities are harmful. As are their negative controlling views about women's bodies. Anti-abortion commentators do not hold the mantle of defining human rights for people with disabilities and our families. Their contribution to the debate on reproductive rights while using the lens of disability is exploitative and confusing. Their emotive language and imagery are not supportive or helpful for people with disabilities."

The use of disability at this time was striking. The law in Ireland was such that disability selective abortions were an impossibility. The criminalization of abortion in all circumstances predated the creation of the Irish state. This had been reaffirmed by a constitutional referendum in 1983 that guaranteed the right to life of the unborn. Legislative discussions at the time were focused on ensuring access to abortion where the life of the pregnant person is at risk.

In spite of this, the conversation continued to focus around disability. With disability being exclusively a characteristic of the fetus, no one could therefore unexpectedly find themselves in a crisis pregnancy.

Disability activists responded to this however, in many respects connecting through the isolation to respond to the campaign.

Many of these conversations were being held in private forums, but much was also made public. The use of technology by disabled activists has long been documented. While technology and the internet has a specific use in connecting communities, this[2] has been particularly transformative for the disability community who face barriers to political involvement.

For many people to whom the community center, the rally or the meeting room was inaccessible, the internet was an accessible alternative.

Two groups of disabled people formed specifically in the run up to the vote on abortion reform.

Disabled People for Choice was formed by a disability activist Evie Nevin in order to amplify the voices of disabled people in the campaign. She used social

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[1] It should be noted that Ireland's disabled persons movement has been going through significant reform since.

[2] Not all disabled people can use technology, and addressing barriers to access to the internet.

media to share the stories of disabled people during the referendum and highlight issues of concern to disabled people.

"Reproductive Rights are Disability Rights" was formed by a group of disabled activists who had joined an online group chat to discuss some of the disability rights issues that were at play during the referendum. The group existed as an online forum for persons to share their experiences and concerns and difficulties with the campaign. They began advising other organizations on language and policies around disability, speaking at events, and hosting online Twitter chats where they held open conversations about disability rights and abortion.

During the final phase of the referendum campaign, both groups joined to form Together For Yes Campaign.

The formation of "Reproductive Rights are Disability Rights" ultimately evolved into Disabled Women Ireland, the national representative organization for disabled women and non-binary people, which continue to advocate for the realization of disability rights on the island of Ireland. We will discuss organizations of women with disabilities at a later point in this chapter.

Globally abortion rights are both expanding and facing unprecedented pushback and how disabled people belong to the struggle for global reproductive rights can often be under question. Bridging the gap between siloed social movements is a challenging task.

Use of International Human Rights Law by Abortion Rights Campaign

Alongside the pushback to anti-choice activists using disability as a justification for restricting abortion rights, disabled reproductive rights activists built a positive disability rights case for abortion law reform. While Ireland only ratified the UN Convention on the rights of persons with disabilities in the months immediately prior to the abortion law referendum, it is clear how the language of Human Rights influenced these arguments.

We described the path to both legal and illegal abortion prior to 2018 in Ireland earlier in this article where activists focused significantly on the access barriers facing disabled women.

Much of the focus of disability rights activists used the language of rights. The right to health (Article 25) featured significantly within the discussions that occurred online and in person. The previous abortion law did not allow for terminations when someone's health, but not life, was in danger, and people were not empowered to make decisions as to what was an acceptable risk to their own health in pregnancy. There was also significant focus on the impact of a crisis pregnancy on someone's mental health, and how ableism and disability-specific barriers could worsen that. The second method by which Irish people accessed abortion was through the importation of illegal abortion pills and self-managing abortion. Disabled feminists also made clear the difficulties this created for them – using the language of rights.

There was also a significant focus on the socioeconomic inequalities and how that impacted disabled people accessing abortion. In Ireland, the rate of poverty was and still is significantly higher among disabled people. Disabled people were less likely to be able to bear the cost of travel and abortion, alongside being less able to afford the specific supports or accommodations they may need.

One strategy pushed by disability activists while working with birthrights and abortion access was to highlight the commonalities between the two movements. Decision-making rights was one element that was consistently raised by disability rights activists. We can see an impact of gender-based discussions on legal capacity and how that impacted discussion between birth rights activists and disability rights activists.

Decision-making rights or legal capacity feature as both a guiding principle and a specific article of the Convention. The values underpinning this right closely overlap the rights that underpin reproductive rights, in particular autonomy and self-determination. During the campaign, activists pushed to recognize this particular intersection, relying heavily on the language of the CRPD (Burns, 2018).

Violations of legal capacity also have a significant gender dynamic and disproportionally impact disabled women. It was noted by the CRPD committee that, “women with disabilities are subjected to high rates of forced sterilization and are often denied control of their reproductive health and decision-making, the assumption being that they are not capable of consenting to sex. Certain jurisdictions also have higher rates of imposing substitute decision-makers on women than on men. Therefore, it is particularly important to reaffirm that the legal capacity of women with disabilities should be recognized on an equal basis with others.”

The national campaign coordinating organization Together For Yes, tweeted a sign from Inclusion Ireland, an advocacy organization for people with intellectual disabilities which campaigned on the referendum. The sign was on the right to make our own decisions and was left over from a march to end guardianship in Ireland.

The birth rights organization AIMS also featured a piece on consent, disability, and pregnancy. This allowed for discussion of decision-making rights beyond the groups that were explicitly concerned with disability and reproductive rights. The piece outlined the overlapping concerns of disability communities.

“Pregnant people all over the country are sharing their stories now. Stories of being demeaned, coerced, and ignored during their pregnancy and birth. Something which is part of the course for many disabled people during medical treatment. The silence around these issues can be crushing. They join the voices of disabled people, who have faced this form of coercion and duress since for decades.”

In spite of these marginal successes, it was noted by Burns (2019) that this failed to bring non-disabled feminist activists to the fight for legal capacity, and while the campaign was ongoing, many decisions were made about the bodies and lives of disabled people. She described an Irish Wardship case that occurred during the campaign. In that case, a disabled woman was ordered to undergo a mastectomy without her consent. Burns asks, “will we wear a badge for her” (Burns, 2019).

While this generated greater understanding between the campaigns, and may impact wider calls, there is no direct link between this campaign and greater solidarity for the disability rights movement.

International Law Building Bridges: Conflict of Rights

Shortly after the abortion campaign, the Committee on the Rights of Persons with Disabilities (CRPD) and the Committee on the Elimination of All Forms of Discrimination against Women (CEDAW) released a joint statement; "Guaranteeing sexual and reproductive health and rights for all women, in particular women with disabilities" – which specifically looked at women with disabilities reproductive rights and affirmed that:

> gender equality and disability rights are mutually reinforcing concepts and States parties should guarantee the human rights of all women, including women with disabilities. As such, States parties have an obligation to respect, protect and fulfil the rights of women, including women with disabilities, in relation to their sexual and reproductive health and rights. States must ensure the enjoyment of their sexual and reproductive health and rights without any form of discrimination. Access to safe and legal abortion, as well as related services and information are essential aspects of women's reproductive health and a prerequisite for safeguarding their human rights to life, health, equality before the law and equal protection of the law, non-discrimination, information, privacy, bodily integrity and freedom from torture and ill treatment. (2018)

This was also followed by the development of the initial draft of the Nairobi Principles by a civil society coalition, which set out a broader framework for addressing the perceived conflict, and once again affirmed that reproductive rights are disability rights, while:

> We recognize that ableism is widespread and that persons with disabilities face diverse forms of discrimination in many aspects of their lives, which are rooted in disability stigma and harmful stereotypes that perpetuate ideas that the lives of persons with disabilities are less valued or that they lack agency to decide on their lives and futures. We will advocate for laws, policies, and practices related to SRHR that do not perpetuate stigma and discrimination against persons with disabilities, and we will consciously avoid using stigmatizing language in our advocacy. (2019)

In 2020, the Special Rapporteur on the rights of persons with disabilities presented a thematic study on the impact of ableism in medical and scientific practice to the Human Rights Council as part of her 2019 report.

The Special Rapporteur stated, "while the issue of disability-selective abortion requires greater attention, solutions must not compromise the right of all women, including women with disabilities, to decide whether or not they want to continue with a pregnancy. As interventions against sex-selective abortions have shown, abortion bans and restrictions on the use of technologies are not only detrimental to women's rights but also ineffective" (2020).

Given the impact of disability selective abortion as an argument to restrict abortion law reforms in Ireland, laying a clear foundation for a human rights focused solution is vital.

Feminist Organizations of Persons with Disabilities

Social movements and international human rights are imperfect tools, complicated systems, which draw often arbitrary, and complicatedly constructed lines. The more nuanced types of oppression experienced by people who don't neatly fit into a single category are rarely addressed.

As noted throughout this chapter, more needs to be done within international human rights law to address these cracks, or to build a new foundation that better serves all people. For disabled women, however, the Convention presents a significant opportunity to forward and advance their rights at a domestic level. While this in part can be attributed to a greater state awareness of this specific type of multiple marginalization or intersectional discrimination, the CRPD presents a framework through which movements can understand each other, establish shared calls for specific rights, and embrace those marginalized within other movements as full, valid, and equal partners who must be heard.

Beyond cross movement organizing, we see the expansion of feminist organizations of persons with disabilities. There is a long history of feminist disabled organizations globally: Women With Disabilities Australia dates back to the International Year of the Disabled Persons, and its first formal construction was in 1985 as a response to the exclusion of women within the domestic and global movement; DAWN in Canada (https://www.dawncanada.net/about/about/) established in 1985; Himpunan Wanita Disabilitas Indonesia (HWDI) (https://www.hwdi.org/), an organization of women with disabilities in Indonesia was established in 1997; the Nepal Disabled Women Association (NDWA) was established in 1998 (https://wwda.org.au/about/our-history/ and https://ndwa.org.np/who-we-are/); National Union of Women with Disabilities of Uganda (NUWODU) established in 1999 (https://nuwoduganda.org/); and the Network of African Women with Disabilities (NAWWD) established in 2004 (http://nawwd.org/category/about/). These organizations developed alongside disability rights within international human rights law and ensured that the treaty clearly articulated the rights of disabled women.

Since the foundation of the CRPD, we have seen an expansion of organization of women with disabilities. Malawi Human Rights for Women and Girls with Disabilities established in 2008, CERMI Mujeres Foundation established in 2014, Disabled Women Ireland on the island of Ireland established in 2018, Artykul 6 in Poland takes its name from the convention, and held its first national congress in 2019, Círculo Emancipador de Mujeres y Niñas Con Discapacidad de Chile – CIMUNIDIS in Chile. This is by no means an exhaustive list of feminist organizing in this area, but it is the continued development and expansion of these groups that is a significant shift in the disability rights movement. This creates space to counter the dominant narrative within the disability rights movement on the feminist movement and allow issues to be discussed and developed.

Conclusion

As well as the creation of new organizations of women with disabilities that are rights focused, the CRPD emboldened organizations of women with disabilities to leverage the language of the Convention to legitimize their claims. The language of Article 6 appears on websites, within policy documents, and within campaigns. Those feminist organizations which had contributed to the development of the CRPD can now rely on it to develop and further their own causes.

The CRPD provides a framework to address feminist and ableist oppression – the focus maps complicated interlocking and overlapping forms of oppression. It is clear from the above analysis, that this complicated framework which is both expansive and well thought out does indeed provide space to address intersecting forms of marginalization both at a global level in the international human rights sphere, and at a local level within domestic civil society. We must recall, however, the single note in the preamble that addresses other intersecting forms of marginalization. Human rights, if it is to succeed, must establish mechanisms to deal with this whether by following the example of the CRPD or by developing new mechanisms to ensure that those in need of rights protections don’t fall through the many cracks within our systems.

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Article 19: Deinstitutionalization and Full Inclusion in Community

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Luke Reid and Roberto Lattanzio

Contents

Abstract

One of the fundamental requirements for the successful deinstitutionalization of persons with disabilities (PwD) is a robust and well-resourced strategy to support their inclusion and independence in the community. A crucial element of this strategy involves the removal of legal barriers that limit their autonomy and independence. However, in many of the jurisdictions where deinstitutionalization has begun, it has

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become clear that government efforts to remove these barriers have fallen woefully short. This chapter will provide illustrative examples of some of the ongoing legal barriers to the inclusion and independence of PwD in Canada, as well as some of the advocacy efforts being made to remove these barriers. Some of the issues this chapter will briefly cover include: (a) accessibility in housing; (b) gaps in the right to security of tenure for PwD; (c) problems associated with complaint mechanisms around the quality of services and support PwD receive; and (d) some of the common forms of discrimination persons with disabilities experience in the area of housing and independent living. In covering these issues, this chapter will use Article 19 of the CRPD to both critique these barriers and to illustrate what the CRPD requires of States Parties when it comes to promoting the independence and inclusion of PwD in the community.

Keywords

Disability · Independent living · Law · Barriers · Convention on the Rights of Persons with Disabilities · Accessibility · Housing

Introduction

Historically, one of the most pervasive rights violations experienced by persons with disabilities has been the denial of the right to live independently in the community. Persons with disabilities have consistently and pervasively labeled in a variety of pejorative medicalized ways throughout history (e.g., “mentally retarded,” “mentally handicapped,” etc.). As a direct result, persons with disabilities have been forced to live, work, and learn in a variety of institutional settings excluded from their communities (e.g., in “mental asylums,” residential institutions, psychiatric hospitals, segregated schools, sheltered workshops, etc.) where almost every aspect of their lives was heavily regulated and controlled. In these environments, their freedom of action and choice was circumscribed to the point where many were largely passive observers to their own lives rather than active participants. This continues to be the case for many persons with disabilities, as many still live in institutional (or institution-like) environments.

This unique history of marginalization was front and center during the drafting of the *Convention on the Rights of Persons with Disabilities* (“*CRPD*”), a convention which heavily prioritizes promoting the right of persons with disabilities to live independently in their chosen community. This right is most directly addressed in Article 19 of the *CRPD*:

> States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:
>
> (a) Persons with disabilities have the opportunity to **choose their place of residence** and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

(b) Persons with disabilities have access to a range of in-home, residential and other **community support services**, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

(c) Community services and facilities for the general population are **available on an equal basis to persons with disabilities** and are responsive to their needs.

Article 19 essentially protects two separate and interrelated rights: a) the right to independent living and b) the right to be included in the community (UN Committee on the Rights of Persons with Disabilities, 2017). Both of these rights are extremely complex – largely because their realization requires the fulfillment of a wide range of civil, political, economic, and cultural rights. The General Comment on Article 19 explicitly recognizes this by designating Article 19 as one of the "most intersectional articles of the Convention" (UN Committee on the Rights of Persons with Disabilities, 2017 at para 6).

This means that States Parties to the *CRPD* cannot realize the full promise of Article 19 without first ensuring that a variety of other important rights are respected, protected, and fulfilled. This is evident in the text of Article 19 itself, which enumerates some of the specific rights that persons with disabilities must have access to if they are to live independently in an inclusive community. These include the right to choose a place of residence, a right to access supportive community services, and a right to access community services and facilities on an equal basis with others.

However, despite the promise of Article 19, independent living in the community remains out of reach for many persons with disabilities. This is often because many of these subsidiary rights remain unfulfilled – a situation which is itself caused by the fact that many of the strategies deployed by governments to support independent living in the community have fallen radically short. In the wake of deinstitutionalization, many persons with disabilities continue to experience a wide range of barriers that make independence and inclusion in the community all but impossible.

One of the most significant barriers is often the law itself. In many countries, a wide range of regressive laws and regulations often remain in place which effectively hinder independent living in the community. This is recognized by the United Nations' recently published guidelines on deinstitutionalization, which emphasize the central role that barrier-laden legislative and regulatory frameworks play in impeding the transition from institutional living to independent living in the community (UN Committee on the Rights of Persons with Disabilities, 2022 at para 60–62). The guidelines suggest that only by systematically reviewing "primary, secondary [and] regulatory. . .sources of law" can we fully identify and remediate the legal barriers that inhibit the full realization of Article 19 (UN Committee on the Rights of Persons with Disabilities, 2022 at para 61).

The purpose of this chapter is essentially to help with this process by identifying some of the legal barriers that operate in Canada to deprive persons with disabilities of their rights under Article 19. In undertaking this analysis, the author hopes to demonstrate how the *CRPD* itself can be used as a tool to critically assess legislation with a disability rights lens. Using Article 19 as a framework, this chapter will highlight some of the distinct obligations that this article places on Canada and some areas where Canada's legal regime falls short. In particular, this chapter will cover some of the legal barriers that (a) prevent persons with disabilities from choosing their place of residence; (b) prevent them from accessing high-quality community supports; and (c) prevent them from accessing many of the community services available to the general public that are required for independent living.

Article 19(a): Choice of Residence and Accessibility

At the heart of Article 19 is a fundamental respect for choice and autonomy, particularly as it relates to ensuring that persons with disabilities can choose where and how they live. As General Comment No. 5 states "[t]o choose and decide how, where and with whom to live is. . .central [to the] right to live independently and be included in the community" (para 24). However, persons with disabilities often cannot choose where to live because of a distinct lack of options when it comes to their living arrangements.

While this absence of choice has *many* different causes, one of the main drivers is inaccessibility in the built environment – a fact which the General Comment recognizes (UN Committee on the Rights of Persons with Disabilities, 2017). Indeed, several cases brought to the Committee on the Rights of Persons with Disabilities raising Article 19 violations pursuant to the Optional Protocol have centered on barriers to accessibility, and the role that local building codes and building regulations play in limiting the options persons with disabilities have regarding their living arrangements (see: *H.M. v. Sweden*, No. 3/2011, CRPD/C/7/D/2011 para 8.9; *Bacher v. Austria*, No. 26/2014, CRPD/C/19/D /26/2014 para 2.1–2.11.) . As a general rule, Article 19 requires States Parties to ensure that new residential construction is barrier free and that existing residential structures are retrofitted to promote accessibility (UN Committee on the Rights of Persons with Disabilities, 2017; Article 9(1)(a) of the *CRPD*).

Unfortunately, Canada is not yet meeting this obligation. Indeed, accessibility barriers in Canada's stock of residential housing represents a significant source of housing instability for persons with disabilities, a fact that has wide-ranging social, economic, and health consequences (Wiesel, 2020). Canada's shortage of accessible housing means that persons with disabilities must often either live in inaccessible housing or face institutionalization. Being forced to live in an inaccessible environment has been linked to significantly greater risk of injury from falls (Burns et al., 2021; Close et al., 1999; Public Health Agency of Canada, 2005; Wiesel, 2020), something which represents one of the leading causes of hospitalization and loss of function among older adults. This in turn often leads to greater unwanted institutionalization (e.g., long-term care), as those who have injured themselves find it difficult to transition back home (Lantz & Fenn, 2017; Scuffham et al., 2003).

Conversely, those who are lucky enough to live in accessible environments enjoy a range of benefits. For instance, some studies have found associations between increased accessibility in the home and reduced need for paid/unpaid support (Carnemolla & Bridge, 2016), increased independence and privacy (Lau et al., 2018), and more freedom when it comes to choosing when and how people carry out their daily activities (Aplin et al., 2015). In addition, improvements in accessibility also facilitate an increased ability to engage in social activities (Aplin et al., 2015). For example, one study found that after ramp installation there was a 60% increase in trips out of the home (White et al., 1995) – while others have found that increased accessibility improved family relations by allowing persons with disabilities to take on caregiving roles (e.g., cooking for their children) (Aplin et al., 2015).

Despite these benefits, accessible housing in Canada remains scarce. Although there are few official estimates of this scarcity, approximately half of all households (49%) were built before 1980 (Canadian Commission on Building and Fire Codes, 2020), a time when there were essentially no accessibility standards incorporated into building regulations (Canadian Commission on Building and Fire Codes, 2021). Even since that time, mandatory accessibility standards for housing remain extremely limited, something which has perpetuated what the OECD calls an accessibility crisis in housing (Plouin et al., 2021). Numerous disability groups have persistently highlighted the shortage of accessible housing as one of the primary problems that many persons with disabilities face when trying to live independently in the community (Alzheimer Society of Canada et al., 2017).

The Legal Regulation of Accessible Housing in Canada

While inaccessibility is very much a problem rooted in our physical environment, it is also important to remember that it is a legal problem as well. Laws play an outsized role in structuring the built environment and also have significant potential to shape it in positive ways.

Broadly speaking, the built environment in Canada is regulated by two types of legislation/ regulation. The first, and most important, are building codes, which exist at both the national and provincial level in Canada. However, these codes are also supplemented, in part, by human rights legislation, which imposes certain additional obligations on building owners when it comes to accessibility. This chapter will briefly describe each of these frameworks, and some of the problems associated with them when it comes to promoting greater accessibility.

(a) *The National Building and Provincial Building Codes.*

Canada's *Constitution Act* gives jurisdiction over the design and construction of buildings to the provinces (see: *Oshawa (City) v. 536,813 Ontario Limited*, 2016 ONCJ 287 (CanLII) at para 71; *Mississauga (City) v. Greater Toronto Airports Authority*, 2000 CanLII 16948 (ON CA) at para 38.). Despite this, for a majority of Canada's history the provinces generally refused to exercise this jurisdiction. As J.W. Archer puts it:

> The wealthy citizens of the new provinces – those who could afford to have buildings designed and built – were not inclined to encourage government to put limitations on what they could do with their property (Archer, 2003).

However, as Canada's cities grew, the problems associated with large cities increased (e.g., fire, typhoid fever, small pox, etc.) and the wealthier elements began to realize that these problems did not distinguish between the poor and the rich. As such, political momentum began to build toward a new arrangement which would give municipalities the ability to write and enforce building codes to counter these problems. This power had generally been granted to municipalities (at least in the largest provinces) by 1900. Unfortunately, this new arrangement resulted in a chaotic patchwork of local municipal building regulations across the country, many of which were of suspect quality (Archer, 2003).

In 1941, the Government of Canada responded to this problem by creating the *National Building Code (NBC)*, a "model" building code that was designed to be suitable for adoption "in toto" by municipalities (Archer, 2003; National Housing Administration & Research Council, 1941). Although the *NBC* was not legally binding, the fact that it was developed using the extensive resources of the federal government meant that by the 1970s most jurisdictions in Canada had adopted some form of it.

Since that time, the provinces have become far more active when it comes to developing and implementing their own building codes. However, the *NBC* has continued to play a very significant role when it comes to setting basic building standards across the country. Nine out of thirteen provinces and territories (New Brunswick, Nova Scotia, Manitoba, Saskatchewan, Newfoundland and Labrador, Northwest Territories, Nunavut, Yukon, and Prince Edward Island) have generally foregone the development of their own building standards and have simply implemented the *NBC* within their own jurisdiction (with some limited modifications in certain circumstances) (National Researcher Council, 2020). Of the remaining four provinces, which create and publish their own codes, three of them substantially mirror the *NBC* in terms of its content (Quebec, Alberta, British Columbia) – a fact which speaks to its enduring influence.

Accessibility Problems in the National Building Code

Unfortunately, when the federal government first developed the *NBC*, accessibility for persons with disabilities was not a design consideration. The original building code contained no provisions designed to promote accessibility. Although it has since been modified to promote a measure of accessibility, significant problems remain – particularly in relation to housing. For example, sections 2.1.1.2.(5), 3.1.1.2.(3), and 3.8.2.1(1) all specifically exempt "detached houses, semi-detached houses, houses with a secondary suite, duplexes, triplexes, townhouses, row houses and boarding houses" from having to comply with any of the accessibility standards currently in the *NBC*. This exemption effectively renders a large part of Canada's housing stock inaccessible to persons with physical disabilities – as including accessibility features into these buildings is effectively voluntary.

Even in larger residential buildings, there are few mandatory accessibility requirements in the *NBC.* Section 3.8.2.3(2) states that barrier-free paths of travel are not mandated in larger buildings unless an "authority having jurisdiction" has designated it as a building which is to "be accessible for use by persons with disabilities." This section essentially means that local municipalities must actively designate a building as being "for" persons with disabilities – as opposed to having accessibility requirements that automatically apply. The intent of these exemptions, as it is described in the *National Building Code of Canada's 2015 – Intent Statements,* is to exempt "certain areas of buildings. . . on the basis that it is impractical or onerous to provide barrier-free access" (see: ss.3.8.2.3(2)).[1]

However, there is little to suggest that providing higher levels of accessibility in these areas is "impractical or onerous." This is evident based on the fact that several provincial jurisdictions within Canada have attempted to improve upon the accessibility standards contained in the *NBC.* That is, even while they have broadly adopted the *NBC* as a whole, they have specifically abrogated or altered some of the sections described above. For example, under s. 3.8.2.1(5) of Ontario's *Building Code*, 15% of all units in apartment buildings ("Group C major occupancy apartment building") are required to have a barrier-free path of travel within them (as compared with only those that have been designated by a municipality). This automatically ensures that all large buildings automatically contain at least a subset of relatively accessible units.

Furthermore, Nova Scotia, despite the fact that it has broadly adopted the *NBC*, has also made several modifications to improve accessibility. It has replaced the exemption for detached homes and townhouses (etc.) with several additional accessibility requirements (adaptable housing requirements – see: 3.8.4.1 of *Nova Scotia Building Code Regulations* N.S. Reg. 26/2017).[2] Other foreign jurisdictions have gone even further. *The Building Regulations* (Britain 2015) in the UK have long required that new dwellings of this type meet minimum visitability standards. All of this is to say that even by the conservative standards of many provinces/foreign jurisdictions, significant improvements in the *NBC* are certainly possible – and would almost definitely lead to improved accessibility requirements across Canada.

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[1] These obviously represent just two problems among many in the *National Building Code.* A number of other notable problems exist. For example, one critique of the current standards is that only a portion of persons with disabilities are addressed by the current standards, as these requirements are primarily based on the dimensions required for people who use manual wheelchairs.

[2] Adaptable housing is housing that can be easily renovated to improve accessibility at minimal cost. As noted above, one of the primary housing challenges many persons with physical disabilities experience is related to the evolution of their disability, and the potential that they will experienced increased accessibility needs. In many cases, they may be in housing which is either expensive or impossible to renovate. Adaptable housing is designed to address this issue by including structural features within the housing that minimizes the cost of renovation and maximizes the type of accessibility-related features that could be implemented.

(b) *Antidiscrimination Law in Canada*

In addition to building codes, antidiscrimination law in Canada plays an important role in helping to regulate the built environment. This primarily occurs through the enforcement of human rights legislation (*Council of Canadians with Disabilities v.* VIA *Rail Canada Inc.,* [2007] 1 S.C.R. 650, 2007 SCC 15), which imposes an obligation to accommodate persons with disabilities on housing providers. Housing providers have incurred significant liability in a number of cases as a result of their failure to properly accommodate tenants by providing physically accessible housing (see: *Jacobsen v. Strata Plan SP1773 (No. 2)*, 2020 BCHRT 170 (CanLII); *Devoe v. Haran*, 2012 HRTO 1507 (CanLII); *Manning v. Stoykovich*, 2021 HRTO 5 (CanLII); *DiSalvo v. Halton Condominium Corporation No. 186*, 2009 HRTO 2120 (CanLII); *Di Marco v. Fabcic*, 2003 HRTO 4 (CanLII); *Biggings obo Walsh v. Pink and others*, 2018 BCHRT 174 (CanLII)). However, despite the potential for liability, these laws have proven to be uniquely ill-suited to dealing with accessibility issues.

One of the primary reasons for this is the reactive nature of many of the obligations contained in human rights legislation across Canada – particularly when it comes to issues of disability (Chipeur, 2021). Numerous commentators, as well as some human rights tribunals, have all confirmed that human rights legislation is generally "retrospective and remedial" (*Shuparski v. Toronto (City)* 2010 HRTO 726 (CanLII) at para 37), meaning that accessibility barriers often have to be challenged after they have been erected and even then these barriers can generally only be challenged one by one, on a piecemeal basis (Lepofsky, 2004; Mosoff, 2000). As the Honorable David C. Only (Onley, 2019) reported, in his review of the *Accessibility for Ontarians with Disabilities Act, 2005,* S.O. 2005, c. 11 (the "*AODA*"):

> Rights under …[Ontario's *Human Rights Code*] are enforced on a case-by-case basis… [and] legal proceedings of this type… have proven very cumbersome, costly and time consuming… Removing barriers one at a time has been extremely frustrating for those seeking wider and faster systemic change.

This trend is vividly demonstrated in the limited human rights case law addressing accessibility problems in provincial building codes. In both *Shuparski v. Toronto (City)* and *Malkowski v. Ontario Human Rights Commission* 2006 CanLII 43415 (ON SCDC)*,* two individual applicants attempted to challenge Ontario's *Building Code* O. Reg. 332/12 on the basis that it failed to incorporate sufficiently rigorous accessibility standards into its guidelines, and, as a result, effectively authorized discriminatory conduct by others on a widespread basis (i.e., the construction of inaccessible buildings). In dismissing these complaints, both the tribunal and the Divisional court stated that the enactment of legislation was not a service within the meaning of section 1 of the *Code* and was in any event a policy exercise that was protected by legislative privilege (see: *Shuparski v. Toronto (City)* at para 26). In doing so, these adjudicative bodies radically limited the potential of human rights legislation when it comes to challenging widespread accessibility barriers in residential housing (at least in Ontario).[3]

Unfortunately, at the moment, these cases represent the totality of the jurisprudence on the compliance of building codes with antidiscrimination law in Canada. No constitutional litigation has been initiated, although there is every reason to believe that ss. 7 and 15 of the *Charter of Rights and Freedoms* may have significant relevance for the accessibility provisions in the building code. However, the complexity of litigation of this nature may have discouraged claimants thus far.

Improving Accessibility in Canada

The above discussion suggests that Canada has a long way to go in order to meet its obligation to create an accessible and barrier-free physical environment, particularly as it relates to housing. Article 19 of the *CRPD* requires States Parties who are signatories to the convention to implement building codes that include barrier-free requirements in residential construction. It does so in recognition of the fact that independent and inclusive living in the community is impossible without an accessible built environment. The sections in the *NBC* highlighted above clearly violate these requirements. In order for Canada to comply with its obligations under the *CRPD,* or indeed for any country to comply, sections like these must be revised to ensure that barrier-free construction is the norm, not the exception.

Article 19(b): Access to Community and In-Home Supports

Independent living in the community is not always possible without appropriate supports. This is recognized by Article 19(b) of the *CRPD*, which highlights the fact that parties to the convention have a legal obligation to provide access to high-quality individualized support services that are designed to promote independence and inclusion in the community (UN Committee on the Rights of Persons with Disabilities, 2017 para 28). The General Comment emphasizes that this includes the right to choose both the *type* of services and the service *providers* who deliver them. It also stresses that these services "should be flexible enough to adapt to the requirements of the "users" . . . not the other way around" (UN Committee on the Rights of Persons with Disabilities, 2017 para 28) and that these services must extend to all spheres of life including employment, education, and political/social participation (UN Committee on the Rights of Persons with Disabilities, 2017 para 29–30).

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[3] It is worth emphasizing here that the same is unlikely to be true of the *Charter* in this circumstance. Indeed, the author has previously done work which suggests that a *Charter* challenge on the basis of s. 7 and s. 15 has the potential to broadly challenge some of the accessibility barriers currently embedded in the *NBC.*

Despite the central importance of this obligation, the development of community support services in Canada lags far behind what is needed (Aubry et al., 2014). For instance, as the Select Committee on Developmental Services in Ontario has pointed out:

> . . .individuals and families who need developmental services and supports are in crisis. We heard that after struggling to obtain services and enduring waitlists for years, many families feel pushed to the brink of disaster (Legislative Assembly of Ontario, 2014, p. 3)

Ontario is by no means unique in this respect. The process of deinstitutionalization and the development of community-based supports in Nova Scotia is proceeding at such a slow pace that the province was recently rebuked by the Nova Scotia Court of Appeal, which found that the situation amounted to a violation of the province's *Human Rights Act*, RSNS 1989, c 214 (see: *Disability Rights Coalition v. Nova Scotia (Attorney General),* 2021 NSCA 70). In that case, the Court of Appeal found that the province's persistent failure to provide appropriate supports to persons with disabilities, as compared to those without disabilities, represented systemic discrimination. The court also found that the absence of support had effectively forced many persons with disabilities (including the individual claimants) into institutionalized settings (e.g., locked psychiatric units) while they endured yearslong waits for appropriate community services.

This case clearly demonstrates that Canada has a long way to go when it comes to providing the appropriate **quantity** of services as required by Article 19(b) of the *CRPD*. However, even those who *do* receive appropriate levels of support often experience a number of other problems which inhibit their ability to live independently in the community. The problems are largely associated with the **quality** of the services they receive, a problem which often has its roots in some of the unique legal standards that surround service delivery.

Problems with the Quality of Supports

Persons with disabilities often experience a variety of issues when it comes to the quality of the support they are able to access. For instance, for those who have a physical disability and require attendant care services in their homes, one survey conducted by ARCH Disability Law Centre (2020) highlighted a number of chronic problems embedded in Ontario's home care system. These included difficulties when it came to scheduling support services at reasonable times, problems associated with attendants not showing up, a lack of adequate training for attendants, negative attitudes toward attendants by service recipients, and in some of the more extreme cases abuse was a significant problem.

In the developmental service sector, those with intellectual/developmental disabilities often face their own unique set of problems when it comes to accessing supportive services. One of the primary barriers is related to the failure of supporters/service providers to respect their right to make their own decisions (see: Article 12 of the *CRPD*). While persons with intellectual disabilities often know they have the right to make their own decisions about their own lives, service providers (or other individuals in their lives) frequently prevent them from exercising this right, particularly as it relates to how, when, and where services are provided. A report for the Law Commission of Ontario makes this explicit:

> Instead of having choice over what to eat, some people with disabilities are forced to eat whatever is cooked for them or the same meal every day for years. Instead of having choice over where to go on outings, some people with disabilities are not permitted to go anywhere unsupervised because it is considered unsafe. Instead of choosing how to spend their free time, some people with disabilities are forced to participate in day programs they dislike because it is more convenient for staff to have everyone in the same place. And instead of choosing a support worker with whom they feel comfortable and safe, collective agreements and organizational bureaucracy force many people with disabilities to be supported by a worker who is assigned to them (Joffe, 2010, p. 28)

The problems described above often have their roots in the law. They result, in part, from either a failure of the existing regulatory frameworks to provide persons with disabilities with sufficient enforceable rights (e.g., an enforceable right to quality support) or a failure by service providers to recognize existing rights (e.g., the right to make one's own decisions). Each of these issues will be described in further detail below.

The Absence of Appropriate Quality Control Mechanisms in Attendant Care Services

Given the number of jurisdictions in Canada, and the range of regulatory frameworks dealing with service delivery within each jurisdiction, Canada-wide analyses of quality control mechanisms in attendant care service delivery are quite difficult. However, one of the striking things about many of these statutory frameworks is the absence of enforceable quality assurance standards. That is, persons with disabilities in many of these jurisdictions often have no guarantees when it comes to the quality of service they receive.

Several good examples of this can be found in British Columbia (BC). In BC, support services for persons with intellectual disabilities are often provided by Community Living British Columbia (CLBC), a crown corporation that operates under the auspices of the *Community Living Authority Act,* SBC 2004, c 60. Although this organization has an extensive (some would argue arduous) complaints process, including an "External Review" process which deals with quality-of-service issues, generally the process does not provide complainants with specific and enforceable quality of service rights – in large measure because CLBC retains sole discretion over quality-of-service decisions. While persons with disabilities may use the third-party External Review process to challenge these decisions, the third party can only make *recommendations* about how CLBC should alter the services they provide.

For those who require access to "assisted living residences" (ASRs) in BC, similar problems exist. The province's *Assisted Living Regulation*, BC Reg. 189/2019, made under the *Community Care and Assisted Living Act,* SBC 202, c 75 – contains limited specific requirements about quality of care beyond mandating that service providers create their own policies and procedures to ensure that the services they provide are of sufficient quality. Furthermore, the only complaints mechanism available to residents in ASRs, outside of the service providers themselves, lies with Assisted Living BC – an organization that firmly limits their involvement to "complaints related to health and/or safety" – a limitation which seemingly excludes a range of quality-of-care issues.

Similar patterns can be seen in other provinces as well. For example, in Ontario, many services for persons with disabilities are provided under the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*, 2008, S.O. 2008, c. 14. A regulation issued under this Act, titled *Quality Assurance Measures* O. Reg. 299/10, purports to regulate the quality of care provided by many service providers but does so only by requiring service providers to enact their own policies about quality-of-service issues, while providing vague and generally toothless statements about the rights of residents. Furthermore, it sets up no clear independent mechanisms to resolve quality-of-care complaints. Ultimately, this leaves service recipients with few specific, enforceable rights and few places to complain about quality-of-service issues.

These examples are representative of a broader issue across Canada – namely that persons with disabilities in this type of service setting often do not have: (a) sufficient legal guarantees related to the quality of the service they receive, or (b) access to appropriate enforcement mechanisms for quality-of-care issues. This often leaves persons with disabilities in these settings dependent on the good will of service providers to ensure that they enact appropriate policies guaranteeing quality of service and that after doing so, that said policies are implemented in the actual delivery of quality services.

As the reader might guess, the absence of these legal guarantees and legal enforcement mechanisms directly impairs Canada's ability to meet its obligations under Article 19 of the *CRPD.* This article mandates both a right to high-quality service and access to appropriate dispute resolution mechanisms that "ensure that all decisions concerning independent living in the community can be appealed" (UN Committee on the Rights of Persons with Disabilities, 2017 at para 81). Without these rights, there is often little that many persons with disabilities can do to ensure that they get the support they need to live independently in the community.

Problems Related to Legal Capacity

Persons with disabilities are often prevented by many service providers and/or supporters from making their own choices, and, as a result, much about the basic ordering of their lives is often left to the discretion (and convenience) of others. This situation often arises because of paternalistic attitudes toward persons with disabilities, which manifest in the form of assumptions about their capacity to make their own decisions. These assumptions of incapacity often result in service providers effectively usurping decision-making authority from the individual (Joffe, 2010).

This often happens in a manner that is contrary to existing law. For example, as in most common law jurisdictions, Canadians benefit from a "presumption of capacity," which is a legal concept that states that, unless there is compelling evidence to the contrary, all people over a certain age (typically 18 years) should be presumed to be capable of making their own decisions (see, for example: *Substitute Decisions Act*, 1992, S.O. 1992, c. 30 at s. 2; *Adult Guardianship Act* [RSBC 1996] c 6 at s. 3; *The Mental Health Act* C.C.S.M. c. M110 at s. 2; Peisah et al., 2017). This principle is often ignored in practice in many developmental service settings, where the rhythms of daily life are set by service providers, regardless of whether they have any compelling evidence to doubt the capacity of service users (Joffe, 2010). In practice, as noted above, what they eat, where they go, and what they do are often decided by others.

This is just one example of a common issue in this type of setting – namely that the existing law on legal capacity is often ignored or improperly applied to persons with disabilities in ways that limit their independence and autonomy. However, this is not to say that there are not inadequacies in the law itself. For example, Canada's long-time emphasis on the use of substitute decision-making, on behalf of individual's deemed incapable (i.e., the use of guardians), represents an approach that has long been labeled as discriminatory by many disability advocates (Stanton, 2016). These advocates have emphasized that alternate approaches like supported decision-making represent a more rights compliant approach to dealing with questions of legal capacity. This is largely because substitute decision-making generally involves removing an individual's right to make important decisions about their own life (based on disability/perceived ability), whereas supported decision-making is generally directed toward providing persons with disabilities with the resources, support, and accommodations they need to ensure that they can continue to make decisions about their own lives.

While it is beyond the scope of this paper to delve deeply into the nuances of supported decision-making, it is sufficient to say that in many provinces in Canada, the existing legal architecture does not recognize supported decision-making and that this creates a number of barriers to its implementation (Stanton, 2016). In provinces like Ontario (see: *Substitute Decisions Act, 1992*), where supported decision-making is not recognized, those faced with decisional capacity issues are often confronted with only one formal option to deal with the situation – namely the removal of their legal ability to make decisions and the appointment of a guardian (Law Commission of Ontario, 2017, p. 74). In the context of service delivery, this means that those individuals with guardians have limited input into how, when, and where services are delivered – a situation which significantly limits their autonomy and control over their lives.

This is contrary to both Article 19 and 12 of the *CRPD,* which taken together emphasize that persons with disabilities have the right to make their own choices, particularly as it relates to service delivery (UN Committee on the Rights of Persons with Disabilities, 2014 para 44; UN Committee on the Rights of Persons with Disabilities, 2017 at para 28). These articles both endorse supported decision-making and the recognition that everyone has the legal right to make decisions about important matters that affect their lives. In order to better comply with its obligations under Articles 19 and 12, Canada must implement reforms designed to better protect this fundamental right.

Article 19(c): Access to Services/Facilities Available to General Population

Persons with disabilities need more than disability-related support services to achieve independence and inclusion in the community. They also need to be able to access the same services, facilities, and rights that are typically available to the general public. This is recognized by Article 19(c) of the *CRPD* which emphasizes that community services and facilities that are available to the general population must also be made available to persons with disabilities on an equal basis as everyone else.

General Comment No. 5 states that this encompasses "a wide range of services, such as housing, public libraries, hospitals, schools, transport, shops, markets, museums, the Internet, social media, and similar facilities and services" (para 32). Notably, it also includes access to the type of rights necessary to thrive in the community (e.g., the right to accessible education, employment, health care, etc.) (para 33). In sum, Article 19(c) requires States Parties to create an environment, outside of institutions, that is accessible, inclusive, and nondiscriminatory.

However, despite these obligations significant barriers to community services/facilities remain, many of which derive from legal sources. The full range of such obstacles is too great to cover comprehensively, so this chapter will limit itself to a brief discussion of one or two of these barriers, with the understanding that they represent just a small part of the overall problem.

Access to the Security of Tenure and the Means to Enforce It

One of the key rights that persons with disabilities must access to ensure that they can live independently in the community is the right to security of tenure, a right which provides legal protection against harassment, forced eviction, and other threats. Among housing and disability advocates, this right is viewed as one of the foundations of the right to adequate housing (see: Committee on Economic, Social, and Cultural Rights, 1991). Without this right, it can be difficult to maintain a residence, let alone to thrive in the community.

Beyond having access to the right itself, persons with disabilities also need to be able to access the means to enforce it as well. This typically occurs through provincial tribunals that are charged with enforcing local residential tenancies legislation (e.g., see Part V – Security of Tenure and Termination of Tenancies in the *Residential Tenancies Act*, 2006, S.O. 2006, c. 17). At these tribunals, people facing harassment, forced evictions, or a wide range of other issues can theoretically challenge problematic landlord behaviors. However, numerous problems in Canada often operate to deprive persons with disabilities of both the right to security of tenure and the means to enforce this right at the appropriate tribunal. Each of these problems will be discussed in greater detail below.

Gaps in the Right to Security of Tenure

By virtue of their unique circumstances, many persons with disabilities often live within a wide range of "alternative residential arrangements" in the community. These arrangements include supported living residences, group homes, supported independent living arrangements, assisted living, intensive support residences, transitional housing, and care homes just to name a few. These different types of residences span a continuum between those that offer higher levels of care, support, and treatment to those that offer minimal levels.

While there is little in the way of common terminology to describe these different types of residences (often making cross-jurisdictional comparisons difficult), what is clear is that in many provinces a large portion of these residential arrangements are not covered under residential tenancies legislation. For instance, in the case of "assisted living residences" for older adults, a 2013 report by the British Columbia Law Institute noted that:

> A review of the legislation of other Canadian provinces reveals that only Ontario and Quebec extend their residential tenancy legislation to equivalents of assisted living. In other provinces, residential arrangements similar to British Columbia assisted living facilities either fall outside of the scope of residential tenancies legislation, or exist in a grey area of uncertainty as to whether residential tenancies law applies to them. (British Columbia Law Institute et al., 2013, p. 23)[4]

A review of current residential tenancy legislation across Canada broadly confirms this point, and suggests that a large number of other residential arrangements, often used by persons with disabilities, are excluded from the application of this legislation (see: *Residential Tenancies Act*, SA 2004, c R-17.1, s. 2(1); *Residential Tenancy Act* [SBC 2002] c. 78, s. 4(f), (g); *The Residential Tenancies Act*, CCSM c R119 s. 3(1); *Residential Tenancies Act*, S.N.B. 1975, c. R-10.2, s. 1(1)(b)(xiii); *Residential Tenancies Act*, 2000, SNL 2000, c R-14.1, s 3(4); *Residential Tenancies Act*, RSNS 1989, c 401; *The Residential Tenancies Act*, CCSM c R119 s. 3(1); *Residential Tenancies Act*, RSNWT (Nu) 1988, c R-5; *Residential Tenancies Act*,

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[4] It should be emphasized that this statement also applies to British Columbia as well. While the report emphasizes that the relationship in assisted living is a landlord-tenant relationship, assisted living arrangements "are not currently governed by the *Residential Tenancy Act*, which governs most rentals of living accommodations in British Columbia." (p. 23)

2006, S.O. 2006, c. 17 ss. 5. (k) & 5.1; PEI Reg EC10/89 s. 1; *Civil Code of Québec*, CQLR c CCQ-1991 at s. 1892; *Residential Tenancies Act*, 2006, SS 2006, c R-22.0001 s. 5(c)-(d); *Residential Landlord and Tenant Act,* SY 2012, c 20). Section 3(1)(d) of *The Residential Tenancies Act* of the Northwest Territories provides a typical example, stating that:

> 3.(1) This Act **does not apply** to
>
> . . .
>
> (d) living accommodation occupied by a person for penal or correctional purposes or for the **purpose of receiving in-patient or resident-based therapeutic or rehabilitative care**;
>
> (e) living accommodation established to temporarily shelter persons in need;

While the language of this section may seem limited to hospital-like settings, subsequent cases in various jurisdictions have indicated that a variety of service/housing providers have invoked similar provisions to escape their legal obligations under various residential tenancies acts. Ontario provides an apt example of this phenomenon. In Ontario, while various interpretations of what constitutes a "therapeutic" and "rehabilitative" place of residence have been put forth, one line of cases has found that these exempted residences are not limited to those offering traditional health care services, but that it also includes residences providing "conditions of support" and that the services offered need not be specifically "rehabilitative" but can include other types of supportive services (see: *Smith v. Youthlink Youth Services*, 2020 ONSC 7624 (CanLII) at para 37).[5]

A variety of different housing providers have taken advantage of these exemptions to residential tenancies legislation (Ministry of Housing, 2006; see also: *Smith v. Youthlink Youth Services*, 2020 ONSC 7624 (CanLII); *TET-58815-15 (Re)*, 2015 CanLII 94893 (ON LTB); *TST-01778 (Re)*, 2010 CanLII 67970 (ON LTB); *SOL-45003-14 (Re)*, 2014 CanLII 52441 (ON LTB); *Murray v Salvation Army Bailey House*, 2011 CanLII 94390 (NWT RO); *Grenadier (Tenants of) v. We-Care Retirement Homes of Canada Ltd.*, [1993] O.J. No. 1550; *YWCA NWT v Hashi*, 2021 NWTSC 15 (CanLII); *NOT-18915-15-RV (Re)*, 2015 CanLII 35176 (ON LTB); *CET-70982-17 (Re)*, 2018 CanLII 41842 (ON LTB); *PHS Community Services Society v Swait*, 2018 BCSC 824 (CanLII); Decision No. 1696 RTB (BC) (2012); Decision No. 6472 RTB (BC) 2015; Decision No. 2161 RTB (BC) (2011)). This has led to a situation where many persons with disabilities are deprived of their right to protection under residential tenancies legislation which typically includes the right to security of tenure (e.g., quiet enjoyment of the premises and restrictions on evictions) and the right to access the various landlord tenant

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[5] In practice, it can be quite difficult to determine which housing/service providers actually qualify for this exemption as this is typically seen as a factual issue that must be decided on a case-by-case basis. See: *Smith v. Youthlink Youth Services*, 2020 ONSC 7624 (CanLII) at para 47; YWCA NWT v Hashi, 2021 NWTSC 15 (CanLII).

enforcement systems in Canada. This deprivation has led to a number of problematic practices on the part of certain landlords (both public and private), like the imposition of overly restrictive rules, programmatic requirements as a condition of tenancy (*PHS Community Services Society v Swait*, 2018 BCSC 824 (CanLII); Decision No. 6472 RTB (BC) 2015), or situations where a person with a disability is ejected from their housing because their needs have been summarily "assessed" as being too high for a particular housing provider (what some might consider a defacto eviction that's characterized as a "discharge" instead) (Carter, 2010; Spagnuolo, 2016; Mahoney, 1997).[6]

Many housing providers argue that these exemptions are necessary because the programming they offer is incompatible with various security of tenure rights. For example, transitional housing providers have stated that their programs require tenants to abide by rules related to curfews, chores, guests, substance use, and behavior/safety requirements – all of which they allege is incompatible with a right to reasonable enjoyment of their premises or the right to privacy. Others note that they must be able to unilaterally end tenancies to promote compliance with program objectives (Ministry of Housing, 2016). The degree to which this is true is debatable and highly dependent on the particular program. Indeed, similar arguments were raised regarding "care homes" in Ontario in the 1990s and they have gone on since to be successfully regulated under the *Residential Tenancy Act* (Lightman, 1990).

More importantly though, these arguments sidestep the most important disadvantage that these exemptions impose on many persons with disabilities, namely the fact that they can no longer access an independent forum through which they can raise complaints about their landlord. In absence of landlord-tenant tribunals, there are very few expeditious places that persons with disabilities can go when it comes to dealing with problems with their landlord.

With this in mind, it is difficult to say that Canada's system of rights and enforcement around residential tenancies is equally accessible to all persons with disabilities and that Canada as a whole is meeting its obligations under Article 19 (c) in this respect. In order to fulfill its promise to make rights, services, and facilities equally available to everyone in the community, exemptions like the ones contained in the residential tenancies' acts described above need to be narrowed or eliminated.

Other Barriers to Accessing Residential Tenancy Tribunals

These exemptions are not the only problems facing persons with disabilities when it comes to accessing residential tenancy tribunals. A review of case law suggests that

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[6] At times, this type of eviction may result not in an individual becoming homeless, but instead in greater institutionalization. Persons with disabilities may be "discharged" from a more inclusive community-based setting to a more institutional setting based on their perceived level of need (e.g., a nursing home).

even those individuals who formally have a right to access these tribunals (because their housing is not exempt) face significant difficulties at these tribunals. These difficulties largely center around two specific issues:

A. A failure by residential tenancy tribunals to apply human rights guarantees to their decision-making
B. A failure by residential tenancy tribunals to properly accommodate persons with disabilities during the tribunal process

Failure to Apply Human Rights Guarantees

Tenants with disabilities, and their advocates, have long complained about the fact that landlords rarely attempt to provide them with reasonable accommodation and that landlords, faced with a disability-related problem, often try eviction before accommodation (Carter, 2010). One of the most common manifestations of this problem usually involves a failure to inquire about accommodation needs prior to eviction and/or a failure to properly engage in the accommodation process itself.[7] That is, landlords are often quick to prioritize their rights, as well as those of other tenants (e.g., reasonable enjoyment of the premises), over those of a tenant with a disability instead of attempting to reconcile these rights through a proper accommodation process.

TEL-81015-17-RV (Re), 2018 CanLII 111,868 (ON LTB) provides a typical example. In that case, a landlord attempted to evict a tenant with multiple disabilities, including fetal alcohol syndrome and sleep apnea, as a result of noise disturbances caused by the tenant staying up late at night playing online games. In describing the situation, the tribunal noted that:

> The evidence does not support the conclusion that the Tenant is deliberately causing excessive noise. Rather, the evidence indicates that a symptom of the Tenant's disability is a loud voice which he is often unaware of. Because playing interactive games online can involve speaking into a microphone to other players, the Tenant's voice can become louder than normal.

The LTB denied the landlord's eviction application, specifically noting that "the Landlord did not meet with or talk to the Tenant about other steps that might help

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[7] For example, see: *SOL-94702-18-RV (Re),* 2018 CanLII 141,507 (ON LTB) (Failure to inquire about accommodation needs prior to applying for eviction); *Erika v. David*, 2003 HRTO 13 (CanLII) (Imposition of extra conditions on tenancy because of disability); *Devoe v. Haran*, 2012 HRTO 1507 (CanLII) (failure to properly engage in accommodation process); *Cityviews Village Inc. v. [tenant]*, RTB (BC) Decision No. 6020 (2021) (Landlord pressuring tenant with disability to move out); *TEL-92935-18 (Re),* 2019 CanLII 86,868 (ON LTB) (Landlord not engaging in accommodation process); TEL-81015-17-RV (Re), 2018 CanLII 111,868 (ON LTB) (Landlord failed to inquire about accommodation needs prior to applying for eviction); SOL-66034-15-SA (Re), 2016 CanLII 44,564 (ON LTB) (Landlord failure to provide accommodation to the point of undue hardship); *SWT-97811-16 (Re)*, 2017 CanLII 48,795 (ON LTB) (Landlord failed to inquire about accommodation needs).

[resolve the noise issue]" and therefore had not discharged their duty to properly accommodate the tenant. This failure to engage in the accommodation process is extremely common among landlords and is perhaps a key reason why many eviction applications are brought against persons with disabilities.

Unfortunately, not all residential tenancy tribunals respond to these applications like the adjudicator above did. Many residential tenancy adjudicators across Canada often forget to heed legal antidiscrimination protections and, as a result, these tribunals have an inconsistent record of properly attending to these issues.

Historically, this appears to have been (at least in part) because it was legally unclear whether these administrative tribunals could even apply antidiscrimination guarantees under local human rights legislation. However, the Supreme Court of Canada clarified this issue in 2005, making it clear that these tribunals could indeed apply antidiscrimination protections (see: *Tranchemontagne v. Ontario (Director, Disability Support Program*) [2006] 1 S.C.R. 513, 2006 SCC 14). Despite this clarification, the ability to apply these guarantees is still often ignored or improperly exercised in this context. Indeed, the case law is rife with examples where landlord-tenant tribunals have failed to either properly apply human rights legislation or have ignored it entirely.[8]

SOL-51322-14 (Re), 2014 CanLII 57894 (ON LTB) illustrates this issue well. In that case, a tenant with clear disability-related needs was evicted from their home – with seemingly little to no inquiry into whether accommodations would have been possible. The tribunal, in evicting the tenant, made no reference to the Code, or the landlord's duty to inquire about disability-related needs (*Lane v. ADGA Group Consultants Inc.*, 2007 HRTO 34 (CanLII)).

Accommodation at Residential Tenancy Tribunals

For many persons with disabilities, access to justice hinges on their ability to obtain appropriate accommodations during the administrative tribunal context. In the last 2 years, this issue has taken on increasing importance in the pandemic, when most

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[8] Examples: *TSL-46861-13 (Re)*, 2014 CanLII 23631 (ON LTB) (No reference by LTB to factors to be considered in undue hardship analysis in eviction hearing); *McKenzie v. Supportive Housing in Peel*, 2005 CanLII 12858 (ON SCDC) (LTB decision did not consider *Code* obligations in eviction hearing); *Bronson v. Kingston and Frontenac Housing Corporation*, 2014 HRTO 619 (CanLII) (LTB did not consider accommodation issue regarding a rental subsidy in eviction hearing); *Walmer Developments v.* Wolch, 2003 CanLII 42163 (ON SCDC) (LTB failed to consider landlords obligation to accommodate in eviction hearing); *Ramadhin v. Chavali*, 2014 HRTO 866 (CanLII) (LTB mediator advised applicant he could not raise human rights issues at LTB eviction hearing); *N.K. v. The Owners, Strata Plan LMS YYYY*, 2018 BCCRT 108 (CanLII) (refusal to allow occupant to keep support animal – failure to apply test for discrimination); *Sharp v. The Owners, Strata Plan* BCS 435, 2020 BCCRT 1142 (CanLII) (Failure to properly apply test for discrimination and burden of proof); *Metro Vancouver Housing Corporation v. [tenant]*, RTB (BC) Decision No. 6022 (2020) (No human rights analysis – tenants evicted because of noise from child with a disability); *TST-32086-12-RV (Re)*, 2015 CanLII 71788 (ON LTB) (Failure of LTB to consider *Code* related issues at eviction hearing); *SWL-13871-18 (Re*), 2018 CanLII 42924 (ON LTB) (Failure to consider code related obligations in LTB eviction decision); *TSL-67255-15-RV2 (Re)*, 2016 CanLII 39865 (ON LTB) (Failure to reference *Code* obligations for procedural accommodations).

administrative tribunals shifted to an all-digital format. With respect to landlord and tenant tribunals specifically, numerous organizations have raised significant concerns regarding the degree to which this process is accessible to tenants with disabilities. For instance, a recent report by the Advocacy Center for Tenants Ontario (ACTO) has highlighted a number of significant accessibility challenges persons with disabilities currently face before Ontario's Landlord and Tenant Board. These included problems with existing accommodations, such as lapses in ASL translation and inaccessible or complicated technologies.

The report further noted that participation by persons with mental health disabilities was almost nonexistent in the tribunal hearing processes (ACTO, 2021). In its conclusions, the report specifically questioned the accessibility of Ontario's landlord-tenant processes and noted that in cases where tenants did not show up, adjudicators inquired about their absence in only 30.5% of cases. This is extremely problematic given the numerous challenges that many tenants may face when attempting to participate in a hearing (e.g., the absence of proper notice *SOL-94702-18-RV (Re)*, 2018 CanLII 141507 (ON LTB) at para 3–6, difficulty arranging access to technology, etc.).

Limitations of Current Processes

These barriers to the right to access justice are contrary to the requirements of Article 19. In its guidelines on deinstitutionalization, the Committee on the Rights of Persons with Disabilities states that these obligations require States Parties to remove all of the "environmental, attitudinal, legal, communicational, and procedural barriers" that prevent persons with disabilities from pursuing legitimate claims through courts and tribunals. They state that States Parties must ensure that persons with disabilities are properly accommodated in the legal system and that they have the appropriate legal standing necessary to pursue these claims (UN Committee on the Rights of Persons with Disabilities, 2022). These obligations dovetail with the ones imposed by Article 13, which requires States Parties to "ensure effective access to justice for persons with disabilities on an equal basis with others… in all legal proceedings…".

Canada has clearly not yet met these obligations. Persons with disabilities still struggle to access vitally important security of tenure rights, as well as the right to an independent hearing as it relates to housing issues. Many persons with disabilities do not have access to landlord tenant tribunal processes (because of exemptions for housing providers) or because tribunals fail to properly accommodate their needs – impairing their ability to participate in the tribunal process. In other cases, even when they are able to participate, tribunals fail to recognize many of the fundamental antidiscrimination rights that persons with disabilities are entitled to benefit from.

Ultimately, all of these make them increasingly vulnerable to eviction, harassment, and other housing-related rights abuses, and significantly impair their ability to live independently in the community. As a result, when persons with disabilities encounter challenges in Canada's housing system, the legal system is not always there to help them.

Conclusion

The purpose of this chapter was, in part, to demonstrate how the rights enshrined in the *CRPD* could be used as a tool to critically assess legislation with a disability rights lens. Using Article 19 as a framework, this chapter has highlighted a number of Canada's obligations as a signatory to the *CRPD* and some of the areas where it falls short in their realization. This included a wide range of legal barriers running the gamut from inaccessible building codes to inadequate or nonexistent quality control mechanisms for service delivery. All of these individual problems, while significant on their own, frequently coalesce into a situation where independent living becomes all but impossible for many persons with disabilities.

The compounding nature of these problems highlights the intersectional character of Article 19. This chapter has identified a number of different areas where Article 19 rights intersect with and are dependent on the fulfillment of other articles in the convention. This point deserves special emphasis, because if the right to inclusive and independent living is ever to be realized, a systematic revision of many of Canada's legal structures is necessary – one geared toward filling gaps in Canadian law that perpetuate dependency and exclusion among persons with disabilities. In short, if Article 19 of the *CRPD* is to be fully realized, *all* of the rights in the Convention must be fulfilled.

While the discussion above has been specific to Canada, it is unlikely that many of these barriers are unique to Canadian jurisdictions. Experience has shown that persons with disabilities in different countries often cope with many of the same challenges and problems when it comes to achieving independence and inclusion. With this in mind, it is the author's hope that this chapter will inspire similar critiques of legal barriers in other jurisdictions, so that the promise of the *CRPD* and the right to live independently in an inclusive community will be realized sooner rather than later.

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The Case of the UNCRPD: Fostering a Human Rights-Based Approach to Disaster Risk Reduction and Implementation Monitoring

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Contents

Abstract

International Human Rights Law (IHRL) does not explicitly affirm a right to protection and relief from disaster; however, it is implied in the positive obligations that the right to life places upon States. By recognizing that climate change-driven disasters have a disproportionate impact on the population, thus exacerbating preexisting vulnerabilities in the society and preventing the full enjoyment of human rights, in particular for the most marginalized, the UN Human Rights system has consolidated its focus on the topic, developing a jurisprudence of Human Rights obligations in the context of climate change. UN Human Rights mechanisms continuously stress the relevance of human rights in both Disaster Management and Climate Change Adaptation and Mitigation, promoting the application of a human rights-based approach. UN Treaty Bodies frequently highlight the links between human rights, disaster risk reduction, the United Nations Framework Convention on Climate Change (UNFCCC), and the

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Sustainable Development Goals (SDGs), as well as their common goal of enhancing community resilience through the reduction of vulnerabilities, despite the fact that these frameworks still work in silos.

Considering the parallelism between the evolution of both "disaster theory" and IHRL, the chapter focuses on the need for a human rights approach to Disaster Risk Reduction and Climate Change Adaptation, underlining those principles which makes human rights the basis for an effective people-centered disaster risk reduction. To this end, it looks at the UN Convention on the Rights of Persons with Disabilities (CRPD) as a case study, given that the CRPD contains the only binding provision in IHRL citing "natural disasters" as a situation in which a State Party must ensure the protection of persons with disabilities. For this and other reasons, including the strong paradigm shift entailed in the Convention, as well as its explicit social development dimension enshrined in a standalone provision on international cooperation (Article 32), the CRPD has a huge potential in fostering the implementation of soft law instruments regulating Disaster Risk Reduction, in compensating the current absence of a flagship treaty on the protection of persons in the event of disasters, and in potentially paving the way for the adoption of such treaty.

Introduction

Building on the assumption that human rights are the connecting dots between climate change, disaster management, and sustainable development, this chapter makes the case for the potential of the Convention on the Rights of Persons with Disabilities (CRPD) and its human rights-based perspective on disability to foster the connection between disaster risk reduction (DRR)-related objectives of the various international agendas and the jurisprudence on states' obligations in the context of climate change, compensating the current absence of a flagship treaty on the protection of persons in the event of disasters.

Considering the parallelism between the evolution of both "disaster theory" and international human rights law, and of the concept of protection, this chapter highlights the need for a human rights-based approach to DRR and climate change adaptation (CCA) measures, comparing it with the traditional humanitarian "needs based approach," and underlining those principles which make human rights the basis for an effective people-centered governance of disaster risk reduction.

The chapter then analyzes three aspects of the CRPD. First, the reflection in the CRPD of the broader international human rights law shift from a paternalistic approach to a vulnerability paradigm, which goes from viewing persons with disabilities as "objects" of charity, medical treatment, and social protection toward considering them as "subjects" with rights. Second, the social development dimension of the CRPD, whose main principles reflect and complement those of a people-centered approach to DRR/CCA, thus constituting a point of reference for further mainstreaming human rights into disaster management. Finally, article 11 of the CRPD is the only binding international provision so far explicitly mentioning "natural disasters" within the situations in which a State party is required to "ensure protection and safety of persons with disabilities."

Drawing upon these reasons and considering that disaster management is currently regulated only by soft law instruments, such as the Sendai Framework for Disaster Risk Reduction 2015–2030, the chapter analyzes the International Law Commission's Draft Articles on the protection of persons in the event of disasters and its understanding of the current jurisprudence, as well as the role that UN Treaty Bodies, in particular of the CRPD Committee, play in fostering the implementation of human rights-based DRR/CCA measures.

Human Rights: The Normative Nexus Between Climate Change, Disasters, and Development

Disaster management and climate change action have historically been perceived as highly technical disciplines, and the relevance and the utility of human rights has been neglected or, at least, scarcely considered until recently. A human rights framework offers an understanding of the different requirements and vulnerabilities of disaster- and climate change-affected persons, as well as their empowerment as rights-holders rather than victims or mere recipients of humanitarian action and relief. Human rights thus contributes to the strengthening of the whole community resilience [intended as a process in which a hazard-exposed system, community, or society is able to adapt, by resisting or changing, in order to keep an acceptable level of functioning. Resilience is a function both of the degree of self-organization and of the community's capacity, based on lessons learned, to adopt measures that concretely contribute to risk reduction] and enhances the accountability of duty-bearers vis-à-vis rights-holders (Kälin, 2011).

International human rights law (IHRL) does not explicitly affirm a right to protection and relief from disaster; however, according to relevant jurisprudence of the European Court of Human Rights (see: ECtHR, ÖNERYILDIZ v. TURKEY, 2008), it is implied in the positive obligations that the right to life places upon States. These obligations on States include the duty to prevent and to mitigate the consequences of foreseeable disasters by adopting, for example, appropriate laws and the necessary institutional and administrative arrangements, by adequately informing the population, and by ensuring liability and accountability of duty-bearers (Kälin & Dale, 2008).

UN Treaty bodies (UNTBs), charged with the monitoring of the implementation of UN human rights legal instruments, unceasingly stress the relevance of human rights in both Disaster Management and in Climate Change Action (CCA), contributing to shape States' behaviors and promoting the application of a human rights-based approach. For instance, UNTBs have been quite active in acknowledging the disproportionate impacts of climate change-driven events on groups in vulnerable situations, such as rural women, children, persons with disabilities, and Indigenous people (see CEDAW Concluding Observations on Bahamas, 2018), stressing the need to take their views into account in a free, informed, and participatory decision-making process.

UNTBs have also frequently highlighted the links between human rights and the international legal and soft law instruments related to human and environmental protection, disaster risk reduction, and climate change (UN Committee on the Elimination of Every Form of Discrimination Against Women (CEDAW), 2018) (such as the Sendai Framework on Disaster Risk Reduction (2015–2030); the United Nations Framework Convention on Climate Change (UNFCCC); and the 2030 Agenda, and the 2016 World Humanitarian Summit), in line with the recent attempts to connect these heterogeneous fields through the main principles of the promotion and protection of human rights and a further acknowledgment of the need for a more consistent human rights-based approach in these areas.

It appears that human rights are the connecting dots between climate change, disaster management, and sustainable development at the UN level, somehow overcoming the integration issues at the international policy and institutional level. Nevertheless, if drawing the link between disaster risk reduction (DRR), CCA, and sustainable development is conceptually easy – they all share the common goals of reducing vulnerabilities and making communities resilient – there is a tendency to consider CCA as separated from DRR, resulting in poor integration and in ineffective strategies and action plans. The different legal status of these international instruments raises integration issues as well, especially considering that, technically speaking, CCA measures (which are regulated by a binding tool) can be considered a subset of DRR (regulated by a nonbinding framework). Placing both CCA and DRR under the umbrella of sustainable development (also regulated by a nonbinding instrument) raise some questions concerning the legal status of a possible new international regime as States would not easily accept to place sustainability goals under a legally binding instrument such as the UNFCCC, considering the widespread climate-related political dissent (Buffet & Revet, 2017). One of the major issues regarding these varied international frameworks is their synergetic implementation on the ground, in particular at the local level.

To achieve this, the need of an integration between those fields and human rights must be acknowledged first at the international level, to spread to the regional, national, and subnational levels. In fact, the mere existence of a national legislation covering DRR has been proved to be not as effective to protect individuals in disaster scenarios as one incorporating human rights (da Costa & Pospieszna, 2015). When human rights are respected and fulfilled, communities present higher level of resilience, intended as the ability of a system exposed to hazards to resist, absorb, accommodate, and recover from its effect in an efficient and timely manner (Bizzarri, 2012).

The Need for a Human Rights-Based Approach to DRR and CCA

To demonstrate the enhanced effectiveness of Human Rights-based DRR and CCA, it is useful to recall the similarities in the evolution of both disaster theory and IHRL. The conception of "disaster" has gradually shifted from inevitable "Acts of God" – predicated on fate which cannot be controlled; thus, nothing could be done in advance with no human responsibility to be claimed (Sun, 2016) – to disasters as

“Acts of Nature” with the 1775 Lisbon earthquake, when the State accepted the responsibility to mobilize the emergency response and to implement reconstruction efforts (Dynes, 1999).

Toward the mid-1970s, the human dimension became part of the disaster equation, conceiving catastrophes as the result of intersection between unaddressed social needs and structural vulnerabilities. Under this perspective, the affected population is no more a victim of the disaster itself but of those in power who have contributed to create (by action or inaction) the conditions leading to their vulnerability. The unequal exposure to risk is due to the dysfunctionalities of the social system that makes some groups of persons more vulnerable to hazards. Disaster risk is socially distributed and follows the pattern of preexisting inequalities, making marginalized groups more prone to death, injury, economic loss, and physical and psychological impairment (Peek & Stough, 2010a). This recognition is conducive to the moral and legal responsibility of who should bear the costs of all phases of disaster management and paves the way for solutions addressing the root causes of social injustice and human vulnerabilities to hazards (Lauta, 2016).

Similarly, IHRL has moved from a paternalistic approach to a vulnerability paradigm that allows to consider the latter not as an intrinsic characteristic of the individual but as the lack of effective legal protection in the enjoyment of rights provided by the public authority. This change of paradigm can be traced in the Convention on the Rights of the Child (CRC), whose cornerstone principle is “the best interest of the child” that must be upheld as the primary consideration in all actions regarding children (CRC, article 3). It perfectly reflects the shift from a “traditional welfare or paternalistic approach” (Crock, 2016) to the right of children to be regarded as active agents. The Committee on Economic, Social and Cultural Rights (CESCR) developed a consistent vulnerability paradigm with regard to the right to housing and adequate standard of living. Although still unclear, the conceptualization of vulnerability of the CESCR Committee is built upon the lack of full and equal enjoyment of the right to adequate housing, suggesting that the discrimination comes from factors such as age, disability, and socioeconomic conditions. According to this construction, disaster-affected persons are a marginalized group as they do not have full access to the right to house and adequate standards of living: Their vulnerability is already existing when the disaster strikes, and it is not to be ascribed to innate characteristics (Nifosi-Sutton, 2018a). Hence, this “new” paradigm recognizes disaster-affected people as victims of the public authority’s negligence in tackling the dysfunctions of the society that are responsible for creating vulnerability, by acknowledging the centrality of the respect for human dignity in protection frameworks. Indeed, in doing so, IHRL has become a core component of protection norms, forming a reliable framework for individuals’ protection during disasters.

Thus, it is evident that human rights play a fundamental role in disaster management and DRR as they provide a legal source of obligations for States in a field so far comprehensively regulated only by soft law instruments. In this way, IHRL represents a legal source of obligation for States in the field of disaster management, imposing procedural, substantive, and specific duties that impact vulnerable groups

(Nifosi-Sutton, 2018b). The recognition that IHRL is relevant not only in the aftermath of disasters but also in the mitigation phase highlights that, when governments are unable or unwilling to minimize the risks and damages of hazards leading to disasters, they violate human rights and must be held responsible for that (Ferris, 2014). Thus, framing DRR measures as human rights issues, other than contributing in reducing vulnerabilities, improves accountability in case of negligence of disaster management actors and empowers individuals and their participation in related decision-making. DRR measures have been defined as an "enabler of human rights" (Sossai, 2018a), referring exactly to the empowerment of individuals and communities vis-à-vis disasters through enhanced participation in political life and consultation in decision-making processes. DRR measures are, per se, a reminder of the necessity to pay attention to human rights standards in policy formulation: In fact, rights-based policies and programs focus on tackling the root causes of vulnerability through the eradication of poverty and by fostering social justice and meaningful participation and consultation, and by addressing multiple forms of discrimination. Moreover, a human rights-based approach considers not only State behavior but also those of nonstate actors, thanks to the consistent IHRL interpretation in the sense that private sector activities shall not interfere with the enjoyment of human rights (OHCHR, 2011). Finally, IHRL is conducive to a people-centered approach, which is supposed to be more effective in adequately addressing the exposure to risks and the vulnerability of communities, compared to top-down, hierarchical approaches (Da Costa, 2014a). Such an approach is the natural consequence of incorporating human rights in DRR, leading to a better disaster governance based on a multistakeholder and a multi-duty-bearers approach, encompassing, as a minimum, the principles of accountability; accessibility of information; meaningful, active, and free participation; and nondiscrimination (Da Costa, 2014b).

The Disability Rights Perspective and the Convention on the Rights of Persons with Disabilities

The UN Convention on the Rights of Persons with Disabilities (CRPD) demonstrates that mainstreaming human rights standards makes the management of disasters, in particular DRR and CCA, more efficient and effective and that its principles and formulation provide a guidance on how to formulate and implement human rights-based DRR.

The CRPD, with its social and human rights-based approaches to disability, reflect the broader evolution of the IHRL paradigm, shifting from a disempowering and stigmatizing charitable view (OHCHR, 2014a), and a biomedical approach that represents "an ideological construction of disability through individualism and medicalization" (Degener, 2016a), to a clear recognition of the enjoyment of rights by persons with disabilities in identifying them as rights-holders, holding duty-bearers accountable.

The social model of disability enshrined in the CRPD sees disability as a social construct, resulting from the interaction between the individuals and an environment that fails to accommodate their difference. The inability of society to eliminate barriers is what creates inequality, rather than the individual's impairment. According to this approach, the public authority (the State) and society are the duty-bearers, accountable for accommodating the requirements of persons with disabilities. Clearly, the view on disability has started to drastically change with the introduction of this model: Disability is a layer of human diversity. This model is in direct opposition to the charity/medical model of disability. Moreover, a social model understanding of disability and a rights-based approach dictates that laws and policies should be designed with the involvement of persons with disability (OHCHR, 2014b).

The human rights approach to disability builds on the social model: It ensures the full and equal enjoyment of all human rights to people with disabilities and promotes the respect of their inherent rights. The foundations of this approach are the principles of the equality of opportunities, of nondiscrimination on the basis of disability, and of participation in all aspects of public life. Barriers constitute a significant source of discrimination, and the State is responsible for their removal, obliging the public authority to undertake actions to ensure the full inclusion in all social aspects (i.e., law enforcement, awareness raising policies, equal recognition before the law, and private sector regulation). This model defies the presumption that impairment might hinder the capacity of enjoying rights (Degener, 2016b). Driven by the core principles of human dignity, individual autonomy, freedom of choice, and independence, this model celebrates human diversity (OHCHR, 2014c) by providing, when needed, support to people with disabilities to exercise active agency in society (OHCHR, 2014d). The human rights model of disability codified by the CRPD is centered on a social model understanding of disability offering a road map for inclusive development and humanitarian aid by seeking to establish the necessary social and economic mechanism to support persons with disabilities to take full charge of their own lives.

Both disaster and disability theory end up recognizing the multifaceted social nature of both disaster and disability. Environmental, institutional, attitudinal, and social barriers are the main source of discrimination in both disability and disasters' modern constructions: Barriers (not the impairment or the person's characteristic) are the source of inequality and must be removed.

CRPD's General Principles and Relevance in Disaster Management

An analysis of the main principles of the CRPD (Article 3) shows full convergence with the principles at the basis of an effective people-centered approach to DRR.

For example, the respect for dignity and individual autonomy translates into the consideration of persons with disabilities not as mere recipients of humanitarian assistance but as active agents. In disaster situations, this principle emphasizes that persons with disabilities have the right to be involved, not only because they can improve Disaster Management with their specific knowledge and skills but also to avoid recurring violations of rights in future disasters (Njelesani et al., 2012a).

The strong nondiscrimination framework of the CRPD allows for the recognition of multiple and intersectional forms of discrimination that persons with disabilities might be subjected to in humanitarian emergencies and provides them with a higher level of protection. The Convention, in fact, moves from a mere proclamation of equality to substantive equality (OHCHR, 2014e).

The meaningful and active participation in decision-making and the inclusion of every diversity is an obligation and an objective of the Convention that oblige States to actively involve organizations of persons with disabilities (OPDs) in the development, implementation, and monitoring of emergency regulation. Mere consultation of persons with disabilities is not enough: Participation must include meaningful involvement in activities and decision-making processes, and the possibility to voice opinions and to correctly identify specific requirements, to influence, and to complain when participation is denied, in line with the disability movement's motto "nothing about us without us." The full and effective participation and inclusion of persons with disabilities in society is a two-way process that promotes the acceptance of persons with disabilities and their participation, and that encourages society to open up and be fully accessible to them.

Respect for difference and acceptance of persons with disabilities reflects the new approach to disability based on the enjoyment of human rights, viewing disability as a part of human diversity. This principle is at the base of Article 8 on awareness-raising, for which States parties are required to adopt measures with the aim "to combat stereotypes, prejudices and harmful practices" and to "promote awareness of the capabilities and contributions of persons with disabilities." It implicates that social programs shall accommodate varying abilities, rather than expecting people to conform to a certain norm, benefitting a broader range of people, such as pregnant women, young children, and the elderly (Njelesani et al., 2012b).

The principle of accessibility is a vital precondition for the effective enjoyments of all human rights and a tool to remove barriers and to grant equality of opportunities (UN Committee on the Rights of Persons with Disabilities (CRPD), General comment No. 2, 2014a). In its General Comment No. 2 on Article 9, the CRPD Committee emphasizes that ensuring full access to the physical environment, transportation, information, and communication is vital for the effective enjoyment of human rights. Thus, in those situations covered by Article 11, emergency services must be accessible to persons with disabilities to save their life or to protect them. Other than stressing on the incorporation of accessibility in postdisaster reconstruction efforts, the Committee explicitly states that "*DRR must be accessible and disability-inclusive*" (UN Committee on the Rights of Persons with Disabilities (CRPD), General comment No. 2, 2014b).

The recognition of equality between women and men highlights the double vulnerability of women with disabilities in disaster settings and calls for States to ensure de facto equality in the access to information of relief projects, to accessibility of emergency equipment and evacuation plans. CRPD Article 6, other than reinforcing the nondiscriminatory approach of the treaty, strengthens this principle with regard to the protection of women and girls with disability from "multiple discrimination," after recognizing that individuals with "multidimensional layers of identities, status and life circumstances" might experience higher disadvantage caused by intersecting forms of discrimination (UN Committee on the Rights of Persons with Disabilities (CRPD), General comment No. 3, 2016).

In a similar way, children with disabilities, who are more exposed to disaster risk, both physically and psychologically, require a special form of protection due to their double status as minors and as having a disability, enshrined in Article 7. As the collapse of social infrastructures, the inequitable access to social services, and the loss of autonomy resulting in dependence increase their vulnerability and decrease their level of resilience (Peek & Stough, 2010b), the CRPD stresses their right to be actively involved in all decision affecting them, as well as the deeper vulnerability they might suffer in humanitarian emergencies.

CRPD: Vulnerability Paradigm, Social Development, and Good Governance

As mentioned above, International Disability Law fully mirrors this paradigm shift of general IHRL, developing its own vulnerability paradigm whose application with regard to legal protection is applicable in emergency situations in general and, as stated by CRPD Article 11, during "natural disasters." The combination of this paradigm with the social development dimension and good governance aspects of the CRPD are conducive to effective, inclusive, and people-centered DRR.

Legal Protection As recalled, the CRPD embraces and extends the ICESCR vulnerability paradigm, providing a higher level of protection due to its robust nondiscrimination framework: The legal protection of the Convention extends to all individuals discriminated on the basis of disability (including perceived disability and discrimination by association). The denial of reasonable accommodation is also considered a form of discrimination, a provision fundamental to achieve equality of opportunity and equality of results. To promote equality, States Parties "*shall take all appropriate steps to ensure that reasonable accommodation is provided*" (Article 5, para.3), and that "*any specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination*" (para. 4). The application of this right (and of the right to equality) is not confined to the rights contained in the CRPD because, as mentioned earlier, any form of discrimination based on disability is prohibited (Cera, 2017a). The provision on reasonable accommodations is a means to achieve one of the objectives of substantive equality: equality of opportunity. Nonetheless, the CRPD requires from States parties an additional commitment to reach equality of results, which addresses the underlining causes of the differentiated treatment. In other words, if equality of opportunities is achieved by providing a sign language interpreter to a deaf person, it does not automatically correspond to the achievement of "equality of results": In fact, societal changes, including the removal and the elimination of barriers, are needed to achieve it (Cera, 2017b). The Convention thus understands human rights from an accessibility perspective and advocates for "transformative equality" as a tool to redress systemic discrimination by undertaking positive actions targeting those social constructs which lead to the exclusion of persons with disabilities and to the denial of their rights. Examples of "transformative equality" are the obligation to provide accessibility, universal design, awareness-raising, and in general, reasonable accommodations to substantive rights. The endorsement to transformative equality is important to empower persons with disabilities and to foster their capabilities through social change. Reaching fundamental structural transformations through reasonable accommodation might result in advantages for third parties as well, for instance, adapting the physical arrangement of a workplace or purchasing new equipment may benefit other employees by making them more productive or by reducing their workload (Cera, 2017c). The concept of reasonable accommodation itself vehicles the idea that the universality of human rights fosters their enjoyment beyond the disability dimension, and the CRPD introduces in IHRL another concept reinforcing this idea: "universal design," defined in Article 2 as "*the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.*" It is evident that its aim is to allow the participation in all aspects of public life to the maximum number of people, having a disability or not.

The CRPD therefore expands the concepts of "equality of results" and of "transformative equality" to develop the model of "inclusive equality," composed of four dimensions: (1) redistributive, to fairly address socioeconomic disadvantages; (2) recognition of human dignity and intersectionality to combat stigma, stereotyping, prejudice, and violence; (3) participative and inclusive, to reaffirm the social nature of people as members of social groups; and (4) "accommodating, to find space for difference as a part of human dignity" (UN Committee on the Rights of Persons with Disabilities (CRPD), General comment No. 6, 2018). Such a construction of the notion of equality could contribute to shape measures to protect persons with disabilities in emergency scenarios, including DRR measures.

Social Development Dimension The CRPD acknowledges the correlation between impairment and increased risk of poverty. The Convention is considered a tool for development (OHCHR, 2014f) because of its stand-alone provision on international cooperation (Article 32), which stresses the role of the international community for the mutual implementation of the CRPD, and implicitly underpins inclusive and accessible development to people with disabilities as a means for the realization of their rights. To do that, the CRPD suggests, on one side, to mainstream the rights of person with disabilities in all development actions and, on the other, to foresee disability-specific measures for capacity building (Della Fina, 2017). Article 32, together with Article 11, attributes three important aspects to development and humanitarian policy, making them binding under international law:

(a) A Human Rights-Based Approach to development and humanitarian aid. Both people living in poverty and persons affected by armed conflicts or natural disasters shall not be treated as objects of charity or welfare but as rights-holders; thus, their opinions must be listened and duly taken into account in every related decision-making process.

(b) Mainstreaming disability in international cooperation to overcome the segregationist structures implemented by traditional disability policies.

(c) The importance of the active and equal participation of OPDs (Degener, 2017). In its General Comment and Concluding Observations, the Committee has cited both the 2030 Agenda for Sustainable Development and the Sendai Framework for DRR as examples of international cooperation.

Good Governance The CRPD, with its provision on active and informed participation and meaningful consultation of every individual in decision-making, creates an environment conducive to "good governance," intended to achieve human development through the guarantee of human rights and with a due regard to the rule of law (Rothstein, 2012). In its General Comment No. 7 (UN Committee on the rights of Persons with Disabilities (CRPD), General comment No. 7, 2018), the Committee has affirmed that an "*active and informed participation of everyone in decisions that affect their lives and rights is consistent with the human rights-based approach in public decision-making processes, and ensures good governance and social accountability*" (para. 2). For the CRPD, inclusive participation and consultation is a fundamental requirement of good governance. In fact, with regard to Article 13 (access to justice), the Committee states that the right of persons with disabilities to participate on an equal basis with others in the justice system includes "*various capacities… as part of the democratic system that contributes to good governance*" and that "*close consultation with persons with disabilities through their representative organizations is key in all processes to enact and/or amend laws, regulations, policies and programmes addressing participation of persons with disabilities in the justice system.*"

CRPD and Inclusive DRR and CCA

The CRPD vulnerability paradigm, its social development dimension and good governance aspects, and its main principles constitute practical guidance to effectively reduce societies' vulnerabilities in the long term as it demands a real commitment toward persons with disabilities that is regularly reviewed.

As discussed above, disaster risk is socially constructed: Disasters are never natural as they are the product of the human interaction with the environment. Hence, reducing the vulnerability and the exposure of the population is key to decreasing the risk of disasters. Persons with disabilities are disproportionately exposed to disasters, emergencies, and conflict situations as society fails to accommodate their different layers of preexisting vulnerabilities even in "normal times." Section "The Need for a Human Rights-Based Approach to DRR and CCA" has also framed DRR as a human rights issue. It was then highlighted that IHRL is relevant for DRR measures as it provides a normative evaluation framework for policy formulation and implementation, enhancing empowerment and accountability while tackling vulnerabilities. IHRL is also conducive to a people-centered approach to disaster governance, which is more effective in the protection of individuals compared to a top-down approach. Section "Human Rights: The Normative Nexus Between Climate Change, Disasters, and Development" has shown that DRR is deeply entrenched with Sustainable Development and Climate Change Adaptation as they share substantive goals and principles. At the UN level, disability is considered both a human rights and a development issue and the CRPD acknowledges this link and recognizes international cooperation and development, including DRR, as tools for the implementation of the Treaty, provided that they follow a human rights-based approach (HRBA) that mainstreams disability and allows for the active and meaningful participation of every person.

The CRPD is thus conducive to "socially inclusive" DRR and CCA measures, which are more efficient than top-down approaches (Le Masson & Lovell, 2017a) in tackling the deep-rooted inequalities that make a society vulnerable to disasters, in understanding why some persons are more excluded than others, and in valuing the diverse characteristics and capabilities of individuals, by recognizing the right of every individual to benefit from and to participate in all phases of Disaster Management. Viewing DRR under a social development lens means not only to promote the full and effective participation of excluded people, by valuing and respecting them, but also to provide and to grant equal opportunities. For instance, in society where women are marginalized, those DRR measures supporting income-generating opportunities to increase women's resources and resilience to disasters incorporate a vulnerability paradigm and follow a social development perspective. Therefore, DRR must cross-cut different sectors to fully embrace a development lens: It must address the conditions that support exclusion, poverty, the access to limited resources, and to promote education, so that in the long-run, systemic inclusion in DRR will tackle social inequalities in a sustainable manner, contributing in reaching poverty eradication in line with the Sustainable Development Goals (SDGs). Thus, inclusive DRR first identifies who the marginalized individuals and groups are in society; second, it recognizes the causes of exclusion; and, third, it involves stakeholders to ensure resilience and accountability in risk governance (Le Masson & Lovell, 2017b).

In this context, legal and social protections are fundamental to protect excluded groups from discrimination and abuses. The protection of persons in the event of disasters is currently regulated by international nonbinding frameworks and national legislations. The CRPD vulnerability paradigm and its discrimination framework not only provide a strong legal framework for persons with disabilities in disaster scenarios through reasonable accommodation and universal design, but also offer guidance for deep transformative changes to tackle systemic discrimination and to foster capacity building more broadly.

The CRPD can be distilled to offer helpful and practical tips on how to apply an HRBA in real practice by following its "twin-track approach" to DRR: empowering people with disabilities by building individual capacity and reducing vulnerabilities, on the one hand; while, on the other hand, developing inclusive DRR policies to increase awareness of people' needs and capabilities and to improve the preparation and training of disaster practitioners.

According to Article 11, the CRPD must be implemented in situations of armed conflicts, natural disasters, and humanitarian emergencies, by including the needs and voices of persons with disabilities in all stages of Disaster Management. The CRPD elements highlighted in the previous sections could represent a way to effectively reduce vulnerability in the long term (Kelman et al., 2017a), providing a practical guide to make DRR inclusive as it requires a commitment to persons with disabilities, and to review it regularly. This approach involves persons with disabilities in positions of leadership and decision-making processes because they are in the best position to give recommendations on how to be inclusive, to raise awareness on issues that persons with disabilities face, in particular with regard to DRR agencies and organizations, and to build as much as possible using universal design principles (Njelesani et al., 2012c).

Monitoring the Implementation of DRR in Times of Soft Law

The ILC Draft Articles on the Protection of Persons in the Event of Disasters

As of today, the field of DRR is regulated mainly by soft law instruments such as the 2015–2030 Sendai Framework for Disaster Risk Reduction (SFDRR). Considering the intensification in the number, and consequences, of disasters, and an international inclination to improve the institutional and operational effectiveness of humanitarian assistance delivery, in 2007 the International Law Commission introduced the topic of the protection of persons in the event of disasters in its agenda, appointing Mr. Eduardo Valencia-Ospina as Special Rapporteur. In 2016, the Commission completed the second reading of a full set of 18 Draft Articles and recommended the UN General Assembly to elaborate a framework convention based on them (International Law Commission (ILC), 2016). To reach a wider consensus and to tackle issues not consolidated in the practice (Bartolini, 2017), the ILC has followed a dual approach in the elaboration of the Draft Articles. It has tried both to codify the already existing practice and doctrine and to foster its further development, although there is no specification on the nature of each article (Murphy, 2016).

The Draft Articles recognize international disaster law as an autonomous branch of international law whose principal aim is: "*to facilitate the adequate and effective response to disasters, and reduction of the risk of disasters, so as to meet the essential needs of the persons concerned, with full respect for their rights*" (Draft Article 2). DRR falls in the scope of the Draft Articles, and it is the subject of Draft Article 9 (Reduction of the risk of disasters): In its broad scope, the duty to reduce the risk of disasters is drawn from principles emanating from IHRL, IDL, DRR, and Climate Change instruments. Its content is shaped by the due diligence approach typical of International Environmental Law, leaving States a margin of discretion on the measures to take, providing that they adopt a certain conduct (Zorzi, 2018). With this progressive Draft Article, the ILC endorses the recognition of the essential role of DRR by the international community, as enshrined in the SFDRR 2015–2030, with its strong call for "*accountability for disaster risk creation … at all levels*" (United Nations, 2015–2030).

The ILC Draft Articles acknowledge the importance of human rights in disaster settings: the commentary on draft article 9 (Disaster Risk Reduction) states that "*protection entails a positive obligation on States to take the necessary and appropriate measures to prevent harm from impending disasters*" as confirmed by international tribunal jurisprudence affirming the duty to take preventive measures (ILC, 2016).

The ILC stresses for the reduction of risk caused by a hazard as distinguished from the prevention and the management of disasters. The ILC Draft Articles reaffirm the fundamental principles of State sovereignty and nonintervention while stating the existence of a primary duty of the State to establish a normative and administrative framework on DRR that follows a due diligence approach in identifying, mitigating, and accounting for the negative impacts caused by human activities (Sossai, 2018b). Draft Article 5 reaffirms the general rights-based nature of the Draft Articles as "*persons affected by disasters are entitled to the respect for and protection of their human rights in accordance with international law*"; however, the rest of the Draft Articles are more duty-oriented, focusing on the rights and obligations of the State vis-à-vis other States, rather than those of the States toward individuals (Hesselman, 2018). The Special Rapporteur himself recognized the presence in the Draft Articles of a tension between the protection of the rights of disaster-affected persons and the principles of territorial sovereignty and noninterference in internal affairs of the affected States. Some authors (McDermott, 2018) claim the ILC has been cautious about a full embracement of a human rights-based approach to the protection of persons in the event of disasters, probably anticipating the reactions of UN Members States, who have a general preference for soft low outcomes as they infringe less on their sovereignty. Consideration of the Draft Articles by the General Assembly, originally scheduled for September 2020, has been deferred to the 78th session of the Assembly in 2023.

Today, the "Draft Articles on the protection of persons in the event of disasters" held a nonbinding legal status; nevertheless, they have already allowed for a better understanding of international legal obligations in the context of disasters, and promoted the development of a more coherent body of IDL, by overcoming that sectoral approach that has traditionally characterized this branch of law (Cubie, 2017). Moreover, as it has happened for the ILC's Draft Articles on State Sovereignty, which were cited by courts and tribunals prior to their formal conclusion, the Draft Articles on the protection of persons in the event of disasters could be used in a similar way. As a matter of fact, because of their strong persuasive character, other than addressing the fragmented nature of IDL and encouraging its progressive development and codification (Connolly et al., 2016), the Draft Articles on the protection of persons in the event of disasters could significantly shape the planning and implementation of national Disaster Management policies to ensure an enhanced level of human rights protection. The ILC Draft Articles could also play a role in the monitoring of human rights by UN Treaty Bodies.

Despite having a strong human rights grounding, as recalled, the SFDRR does not pose any binding obligations upon States. Soft law tools present problems in terms of accountability and implementation, even though the SFDRR provides a set of specific indicators to facilitate the States' monitoring activity. The SFDRR is strictly interrelated with the 2030 Agenda for Sustainable Development that has Goals with targets related to DRR, and the SFDRR can contribute to the realization of all the 17 goals and has explicit references to human rights, enshrined in its ultimate aim of "leaving no one behind." Conversely, rights enshrined in human rights covenants and in the CRPD are particularly relevant to better understand the 2030 Agenda and to practically implement the SDGs. In particular, the CRPD principles are favorable to the realization of the whole Agenda.

The Role of UN Treaty Bodies UN Treaty Bodies, in charge of the monitoring of Human Rights covenants, can play an important role in supporting the implementation of the 2030 Agenda. In fact, UNTBs and the 2030 Agenda mutually interact in at least two ways. First, by gathering a significant amount of information related to the realization of a specific provision through their reporting procedure, UNTBs become a source of data to monitor the implementation of related SDGs, for example, by requesting data on the employment of persons with disability in the open-labor market in a specific sector (OHCHR, 2016). Second, UNTBs also facilitate the assessment of the "leaving no one behind" principle, focusing the attention on the most marginalized individuals and groups, and driving States' attention to the existence of multiple drivers of inequality and on the social construction of vulnerability. In this sense, UNTBs further strengthen the negative correlation between inequality and development effort, other than just recognizing it as a human rights violation. Henceforth, UNTBs go beyond the mere assessment of the situation of those at risk to be left behind as they actually identify implementation gaps, areas of main concerns, as well as risks and challenges, and suggest the next steps to adopt in their regard. As a matter of fact, UNTBs Committees usually recommend the adoption, the amendment, or the revision of laws and policies that protect individuals against any form of discrimination, including the provision of effective remedies. For example, the CRPD Committee in its Concluding Observations often recommends the inclusion in law of the denial of reasonable accommodation as a form of discrimination, in particular in the field of education and employment (see CRPD Concluding Observations on the Former Yugoslav Republic of Macedonia, 2018). Again, according to UNTBs, the collection of disaggregated data is extremely important for effective disaster prevention and preparedness in order to formulate more tailored and context-specific policies and programs (see CRC Concluding Observations on Saint Vincent and the Grenadines, 2017).

CRPD Article 11 is the only binding provision in IHRL citing "natural disasters" as a situation in which a State Party must ensure the protection of persons with disabilities, which offers huge potential in fostering the implementation of soft law instruments, as it calls for a human rights-based approach to humanitarian assistance (OHCHR, 2015). The CRPD Committee has already developed a consistent practice explicating the measures to take in order to ensure the protection of persons in humanitarian emergencies, including the following: the meaningful participation and consultation of persons with disabilities through their representative organizations; and ensuring that all strategies are inclusive and accessible and in line with the SFDRR by, for instance, optimizing the use of mass media, by providing the necessary assistive devices and by adequately training emergency relief personnel on an age and disability approach. States actions are required by the CRPD in all phases of Disaster Management, from DRR, prevention, and preparedness to rehabilitation and reconstruction, as well as rebuilding processes. The Committee has also stressed the importance of mainstreaming disability in resettlement and refugee policies, and of prioritizing the safety of women and children with disabilities. The Committee has often, though generally, recalled the SFDRR with regard to the adoption of compliant legislation, while it has extensively cited the 2030 Agenda in a very detailed manner. In this way, the Committee has eased States' work in keeping track of their progresses in the implementation of both the Convention and the 2030 Agenda. The CRPD Committee should adopt the same approach when citing the SFDRR so that States could harmonize their efforts, by implementing tailored strategies in line with the two frameworks and the Convention. Moreover, such an approach would also be helpful for all the other stakeholders involved in the monitoring process, such as civil society organizations and national human rights institutions, compensating the lack of expertise on technical topics. Moreover, the CRPD Committee should consider citing the work of the ILC with regard to the protection of persons in the event of disasters in its upcoming General Comment on Article 11, as well as the Sendai Framework and the SDGs, because even in their current nonbinding status, they constitute a strong advocacy tool and an authoritative interpretation to strengthen the interpretation on DRR- and CCA-related provisions.

Conclusion

Although UNTBs outputs are not legally binding, their potential in contributing to the monitoring of the implementation of DRR soft law instruments is not only limited to Concluding Observations and General Comments. Other than the state-reporting procedure, the consideration of individual communication, and its follow-up procedures, contributes to shaping the expectations on what is considered of an appropriate behavior from States, in strengthening human rights standards, and in identifying human rights claims vis-à-vis stakeholders. Most importantly, they reinforce the international obligation to apply a human rights-based approach to DRR and CCA measures and provide specific indications on how to practically implement that approach. Therefore, TBs strengthen the connection between DRR-related objectives of the various international agendas and compensate the current lack of a binding treaty regulating the protection of persons in the event of disasters by also reinforcing the synergetic implementation and monitoring of relevant soft law tools, namely, the SFDRR and the SDGs.

In particular, the case of the CRPD was raised as a demonstration that the mainstreaming of human rights standards can contribute to make the management of disasters more efficient and effective: In fact, through its principles and formulation, the CRPD provide a guidance to formulate and implement inclusive and human rights-based CCA/DRR measures.

There is a full convergence between the main principles of the CRPD and those at the basis of an effective people-centered approach to DRR and CCA. Moreover, CRPD's specific elements lead to effective and people-centered DRR: First, the vulnerability paradigm and the robust nondiscrimination framework enhance legal protection, which is extended to all individuals discriminated on the basis of disability. The CRPD's accessibility perspective entails the concepts of "transformative equality" (obligation to provide accessibility, universal design, awareness-raising, and reasonable accommodation) and of "inclusive equality" (redistributive, combating stigma, participative and inclusive, and accommodating) as tools to redress systemic discrimination, achieve positive social change, and empower individuals with disabilities. Embracing all these elements in disaster scenario means that States must ensure the respect of the principle of nondiscrimination in all emergency programs and actions, by duly recognizing the disproportionate vulnerability of persons with disabilities in evacuation scenarios, by providing accessible information and ensuring that humanitarian aid relief is distributed in an accessible, nondiscriminatory way.

Second, the CRPD stand-alone provision on international cooperation (article 32) implicitly underpins inclusive and accessible development to persons with disabilities as a means for the realization of all their rights enshrined in the Covenant, to be achieved through a twin track approach. In combination with Article 11, Article 32 makes the human rights-based approach to development and humanitarian aid a binding obligation under international law, together with the mainstreaming of disability policies and the importance of equal participation.

Finally, the CRPD, with its provision on active and informed participation and meaningful consultation of every individual in decision-making, creates an environment conducive to "good governance," which is part and parcel of achieving effective DRR and CCA.

Thus, the CRPD and its perspective on disability show a still untapped potential in contributing to the evolution of DRR and CCA measures toward being more human rights based and people-centered, enhancing their effectiveness, as well as in sustaining the development of an organic and coherent legal binding framework to protect persons in the event of disasters.

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Part XII

Disability Activism and Advocacy

Disability Activism and Advocacy: Introduction

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Victor S. Pineda and Serida L. Catalano

Contents

Abstract

The second decade of the twenty-first century has witnessed a multitude of significant changes that have engendered systemic shifts, civic disruptions, and humanitarian crises, which have proven to be especially harmful to those who are most at risk of exclusion, in both the global North and South. In this context, disability activism and advocacy assume a pivotal role in reshaping and restructuring societies, and redefining our conceptualization of emancipatory politics, equity, rights, space, and democracy. Indeed, disability justice activists have been and continue to be instrumental in advancing innovative visions, tactics, strategies, and transformational outreach to dismantle institutional, physical, and attitudinal barriers to inclusion.

This introduction provides a comprehensive framework to understand the foundational role of disability justice advocacy and activism and the inescapable challenges that disability activists must confront to promote inclusion for all and contribute to building more resilient, sustainable, and just societies.

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Introduction

The second decade of the new millennium has seen a flood of technological, political, socioeconomic, and cultural transformations. These changes are led in part by systemic shifts, which have caused a surge of instability, civic disruptions, austerity, lockdowns, pandemic outbreaks, protracted conflicts, and humanitarian emergencies. The rights of those at the margins of society are particularly at risk, both in the global North and South, and it is imperative to understand what tools and strategies are available to ensure that all transformations which are required to build a more resilient and sustainable future are also inclusive for all.

Over 15% of the world's population has a form of impairment (WHO, 2011) and with a progressively aging world population and the emergence of non-communicable diseases in low- and middle-income countries; the number of persons with disabilities is predicted to further increase. While disability activism is often incorrectly viewed as only about disability "rights" with limited political impact, in fact, disabled people, disability activism, and advocacy hold a crucial role in transforming both culturally and structurally our societies, by bringing about strong repercussions in our conceptualization of emancipatory politics, rights, space, and democracy itself.

In this section, we aim to emphasize the foundational role of disability justice activists and how activism across the world brings together tactics, strategies, and their transformational outreach. The conceptualization of activism is ultimately connected with that of the border (Brambilla, 2012, Lafanzani, 2012), in that any struggles highlight a separation between insiders, that is right-holders and, outsiders, not holders in the juridical sense of the term. In particular, as Nyers (2008) points out, activism is a vocalizing act of citizenship and is one of the activities that advocacy uses to reach targeted stakeholders. Disability advocacy is defined as any action that speaks in favor of, recommends, argues for, demands, supports, defends, or pleads for or on behalf of social and spatial justice for persons with disabilities. It promotes equality, social justice, social inclusion, and human rights for persons with any type of impairment and aims to eliminate social, physical, and institutional barriers. Disability advocacy recognizes that allies matter, but also contends that self-advocacy – whereby people with first-hand lived experience of disability, perhaps with encouragement and/or support, speak out and act on their own behalf – is critical to bring about change. Disability advocacy also contends that disability is not simply a medical condition or an illness but a social construction and has largely focused on repairing the toxic social isolation, discrimination, neglect, and abuse created by systemic ableism, thus succeeding in rewriting the way in which individuals with disabilities can define – and be defined by – society.

An ableist framework inherently links a "normal" set of human functionings with standards tied to a "normal body." As Rodas (2009, 837) argues, "[w]hen people speak of the social construction of disability, they refer to the view that disability is a social invention, a category determined not by the physical body but by external factors." Such external factors include social, physical, and/or institutional barriers that limit the freedoms of persons with disabilities to participate on an equal basis with others. According to this view, “while people with disabilities may be characterized by some form of physical impairment – blindness, deafness, or paraplegia – the physical condition of the body is secondary to the way that body is defined socially” (Rodas, 2009, 238). From this perspective, disability is “a product of the interaction between the individual and the environment” (Hahn, 1985).

Thus, disability originates from a society whose design or attitudes discriminate against impairment, not simply from the physical composition of the body and/or cognitive structure of the brain. So far, an inclusive space is a place where everyone, regardless of their economic means, gender, ethnicity, disability, age, or religion, is enabled and empowered to fully participate in the social, economic, cultural, and political opportunities that cities have to offer. Inclusive environments consider people’s diversity and break down unnecessary barriers and exclusions in a manner that benefits all. In the urban environment, realizing the politics of difference means building spaces that do not create barriers or prevent participation, and rather promote and defend the access of all groups. It follows that when disability advocates talk about disability as a social construction, it becomes a social and spatial reality that cannot solely be tended to by medical professionals. It must rather be addressed by planners, policymakers, and designers who understand the nuances and diversity of the human condition. Disability advocacy thus brings into focus the enabling and disabling roles of environmental design and raises the possibility of constructing more flexible, sustainable, and just cities.

At the core of disability advocacy lies, the belief that participation is the primary tool for unlocking new capabilities in individuals and in groups, and allows otherwise marginalized individuals to address their respective deprivations by influencing the processes of public decision-making. As the chapter of Maria Soledad Cisternan will show, the negotiation process of the UN Convention on the Rights of Persons with Disabilities (CRPD), as well as its outcomes, have been crucial in asserting the meaningful and effective participation of persons with disabilities as is witnessed by the motto “Nothing about us without us.” The CRPD was the result of a concerted effort of disability advocates whereby people with disabilities affirmed the need to be consulted in all matters affecting their lives, rather than being subjected to decisions made on their behalf.

The participatory processes of persons with disabilities, through organizations of persons with disabilities and their partners, in the negotiation and drafting of the CRPD strongly influenced the outcomes of the Convention and its relevance for persons with disabilities, becoming a striking example of the principle of participation. Indeed, the CRPD enshrines the obligation of States parties to closely consult and actively involve persons with disabilities (art. 4 (3)) and the participation of persons with disabilities in the monitoring process (art. 33 (3)) as part of a wider concept of participation in public life. In addition, through the CRPD, people with disabilities and their representative organizations also generated a consistent paradigm shift from the medical/charity model of disability to the social/human rights model of disability.

The medical model (or biomedical model) considers disability as a problem of the individual that is directly caused by a disease, an injury, or other health conditions, and requires medical care in the form of treatment and rehabilitation (Mitra, 2018). The medical model attributes the problem to the individual, who has a condition that is unwanted and that places him or her in the "sick" role with the aim to "cure" or "treat" (Mitra, 2006). Such a model is based on "divergence from a capacity of conducting current activities considered as a norm" and thus views disability as an inherently limiting characteristic of the individual (Trani et al., 2011).

The CRPD conceptualizes disability through the social/human-rights model, which defines disability as the result of the interaction between people living with impairments and an environment filled with physical, attitudinal, communication, and social barriers. The Convention, therefore, implies that the environment must change to enable people living with impairments to participate in society on an equal basis with others. Unlike the charity or medical model – in which people with disabilities are "objects" of charity, medical treatment, and social protection – the social/human rights model views people with disabilities as "subjects" with rights, who are capable of claiming those rights, able to make decisions for their own lives based on their free and informed consent and be active members of society. According to Nagata (2008), who has been actively involved in the CRPD and in promoting disability-inclusive development throughout her 24-year career with the United Nations, a rights model of disability should integrate three key perspectives and create a space to operationalize local solutions. Her model recognizes:

1. The mutual and dynamic interaction between a disabled individual and their social environments (e.g., social barriers, attitudes, and accessibility).
2. The diversity existing among different types and categories of disabled persons and the difference in their needs and priorities.
3. The relevance of the human-rights-based approach to individual disability experiences in diverse local cultures and customs.

What is innovative about the human rights model is the central role that social barriers and attitudes play, as well as the cultural context of diverse individual disability experiences. In fact, the conceptualization of disability under the lens of the social/human rights model and the principle of participation enshrined in the CRPD are the result of a long battle of disability activists, of which the negotiation and drafting of the Convention is the culmination. As it is sketched out in our chapter in this section, disability advocates in the US shaped new policies, programs, and initiatives framed on a social model of disability to undo generations of harm perpetrated by urban planners who conceptualized disability as a medical abnormality, or social blight. The Independent Living Movement that began across several cities in the 1970s presented, for the first time, a socially and spatially just perspective of disability. This socio-spatial model was seen most clearly in the social justice campaigns of advocates living in Berkeley and featured in the Oscar-nominated feature documentary film *Crip Camp*. From Berkeley to Washington D.C., advocates fought to define and assert the right to the city for, by, and with disabled people. For example, in April of 1977, a historic battle took place in San Francisco where advocates, organized alongside a range of other advocacy groups, staged a critical confrontation for social and spatial justice, with a fundamental right to be considered whole and equal members of the societies within which they lived. Some of the practical tenets brought up by disability-inclusive planning are already embodied in key laws protecting the rights of persons with disabilities. Key federal legislation such as the Architectural Barriers Act of 1968, the Rehabilitation Act of 1973, and the Americans with Disabilities Act of 1990 set into motion mandates, standards, and guidelines aimed at advancing employment and the public participation of persons with disabilities by incrementally removing physical barriers from the built environment. New standards in construction, transportation, and design were enforceable by-laws. Disability advocacy literally changed the face of the nation. By identifying and mandating compliance with anti-discrimination law in education, employment, architecture, and transportation, these laws began to empower advocates in San Francisco, Chicago, Los Angeles, Houston, and Eugene, Oregon, to create pockets of radical inclusion that not only benefited disabled people but also older persons, families with children, and individuals who have temporary or situational impairments.

This section is the result of the critical and ground-breaking work of scholars across the world who are advancing our understanding of advocacy and activism work by disability rights leaders in both the Global North and South. We are seeing the enormous successes resulting from the work of disabled activists and their allies, and as our conception of disability has changed considerably, we no longer have to rely on outdated models to understand the meaning and experience of disability. This work has resulted in enormous gains for people with disabilities around the world, but as the number of people with disabilities is expected to increase, it is critical that today's activists have the knowledge and resources to learn from each other in the ongoing fight for access and inclusion.

A thorough review of scholarship on disability advocacy and activism is more important now than ever. This section sheds light on some key aspects of advocacy and activism that illuminate dimensions that are particularly relevant for the second decade of the twenty-first century, such as the institutional (policies, laws, and social reforms), immediate challenges (e.g., humanitarian crises), and inescapable ones (e.g., aging population), as well as technological innovation.

The authors of these chapters understand the critical role environmental design, social acceptance, and government policy have in creating just, sustainable, and inclusive cities for all. It is our hope that this section furthers the ongoing collaborative work of disability activists around the world, providing just one outlet for us to learn from each other. Complex systemic factors are usually baked into institutions that perpetuate exclusion and marginalization through a range of domains ranging from parent's rights, to technology, to urban planning. Institutional failures too often and for too long have completely disregarded the fundamental rights and dignities of disabled people. For this reason, any approach designed to address these issues must be multidimensional and cross-sectional.

Each chapter will highlight some or all of the five pillars for evaluation and assessment of inclusive urban development as simplified by the DisCo Urban Policy Framework (Pineda, 2020):

- Legislative measures: what do local, national, and international laws stipulate with regard to regulating and mandating disability rights and justice?
- Leadership: what has the highest political authority or executive in this domain said publicly on the topic? Is this a political priority? If so, is there adequate budgetary support?
- Institutional Capacity: do key institutions have the necessary administrative and coordinating capabilities to manage and lead transformation across siloes?
- Participation of the targeted group: what mechanisms and norms exist to ensure substantial, authentic, and representative engagement by diverse Stakeholders and other social groups?
- Attitudes toward the targeted group: What are the attitudes of the general community toward persons with disabilities in a specific domain or policy area?

The chapter from Ikponwosa Ero et al. explores the attitudinal barriers faced by people with albinism in Tanzania and the work of a group of mothers and women with albinism to combat these challenges. Though albinism is a relatively rare condition, rates of disability are higher in Tanzania than elsewhere, and those with albinism in Tanzania face significant discrimination in all areas of daily life. The authors demonstrate the significant human rights work of these mothers, drawing from their ethnographic research in the region. The mothers in the study described how they fought for their children to receive education and healthcare, and recounted their children's experiences of bullying, discrimination, and violence. This chapter illuminates how groups, such as the one created by mothers of children with albinism, can be a key site of human rights activism and asserts that States should see these groups as partners and collaborate with them as such.

The chapter from Pineda et al. shows how people with disabilities have long been locked out of the urban environment due to the practices of architects and planners with the result that solutions to address inaccessibility and exclusion have been lacking. Therefore, the chapter explores the intersection of disability advocacy and urban planning, highlighting how disability advocacy efforts have historically focused on undoing the harms of the planning profession and responding to the consequences of social and economic exclusion. These efforts, including the protests for Section 504 and the 1990 Capitol Crawl in support of the Americans with Disabilities Movement, demonstrate the keys ways the Disability Rights Movement has fought to upend centuries of discrimination and exclusion caused by architects, urban planners, and others by also bringing about a new focus in human-centered design and inclusive development.

This chapter from Holness, W. illuminates the context of parent-led activism in South Africa, by highlighting the barriers preventing children with disabilities from accessing education and healthcare, and the work and methods of their parents in agitating for change. While parents are often critical advocates for their children with disabilities and may play a key role in ensuring their children have access to services and education, this chapter also contends that parental activism is rooted in paternalistic beliefs and the medical approach to disability. Moreover, parental advocacy efforts are dependent on the resources available to the family, as advocacy work requires significant time and the capacity to navigate bureaucratic systems. Many of the challenges faced by both children with disabilities and their parents arise from systemic failures, including the widespread exclusion of children with disabilities from schools in South Africa.

The contribution from Maria Soledad Cisternas sheds light on the genesis and implications of the principle "nothing about us without us," which has been a defining slogan of the Disability Rights Movement, asserting that all decisions relating to a disability must be made in consultation with people with disabilities. This chapter illustrates how the principle shaped the development of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), signaling a critical change in the perception of people with disabilities. The author contends that every aspect of the Convention was guided by this principle and illuminates the key ways in which the inclusion of people with disabilities shaped the text.

The chapter from Willis explores the important link between disability advocacy and activism in humanitarian action and its crucial role in impacting the policies, practices, and recommendations set out by international treaties, federal and local legislation, policies, and practices. In particular, central to this movement is a focus on rights, equity, and inclusion, particularly when concerning persons with disabilities and older persons, as well as refugee and displaced populations, who are at an increased risk of experiencing further harm and marginalization as a result of multilayered barriers and compounded (but often inadvertent) discriminatory and exclusionary emergency response mechanisms, human rights and protection systems, and humanitarian action.

The chapter from Mailloux and Ludke focuses on the often unexplored link between disability activism and innovation, which has been made even more relevant by the repercussions of the Covid-19 pandemic and the consequent need to adjust to digital-first communications and hybrid models at work. This contribution aims to compile a wider range of examples of inventions and technologies made possible by the disability community, highlight diverse perspectives from the disability community, and draw recommendations from expert practitioners on the "how" of benefiting from disability-led innovation.

Finally, the chapter from Nzo et al. highlights the crucial aspects and consequences of the aging population worldwide, especially considering the inevitable link between aging and disability. A crucial problem for older people is the risk of institutionalization. This is despite the fact that the literature indicates the reduced costs of living in communities compared to institutions, coupled with evidence showing that older persons and persons with disabilities prefer to stay in their homes and communities. This chapter explores the critical thinking around an institutionalized and independent living arrangement that can enhance sustainability and resilience in community living arrangements and provides the reader with a comprehensive understanding of how movements led by persons with disabilities bring social innovation to activism and advocacy for sustainable and resilient community living arrangements for an aging population.

The authors contributing to this section all understand the critical role environmental design, social acceptance, and government policy have in creating just, sustainable, and inclusive cities for all. It is our hope that this section furthers the ongoing collaborative work of disability activists around the world, providing just one outlet for us to learn from each other.

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Women Human Rights Defenders: A Case of Activism of Mothers of Children with Albinism in Tanzania

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Contents

Abstract

Human rights activism is often undertaken by human rights defenders (OHCHR [Office of the United Nations High Commissioner for Human Rights], *Who is a defender*. https://www.ohchr.org/en/issues/srhrdefenders/pages/defender.aspx, 2020). The most obvious human rights defenders are those working in organizations dedicated to human rights. It is neither the role nor institution that

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determines if one is a human rights activist or defender but rather the "human rights character of the work undertaken" (OHCHR, *Who is a defender*. https://www.ohchr.org/en/issues/srhrdefenders/pages/defender.aspx, 2020, para. 18). The activism carried out by the network of women impacted by albinism in Tanzania, consisting of women with albinism and mothers of children with albinism – the latter being the primary subject of this chapter – bears the hallmark of human rights. The Mamas' Groups, as they are commonly known, work and live in rural conditions with many of them being illiterate. The mothers, as the data will demonstrate, have undertaken human rights work in the advancement of both their rights and those of their children.

Keywords

Albinism · Human rights · Women human rights defenders · Mothers · Parent-led advocacy · Tanzania · Children with albinism · Mamas' Groups

Introduction

In this chapter, we present an analysis of the activism of the mothers of children with albinism, a relatively rare and little-understood disability, through the conceptualization of their rights. We draw on a study on mothering, albinism, and human rights underway in Tanzania (Social Sciences and Humanities Research Council Canada #435-2019-1120), and the work of the United Nations (UN) Independent Expert on the enjoyment of human rights by persons with albinism with the mandate to conduct official country visits, and survey persons with albinism and their representative organizations. We provide insights into the stigma and attitudinal barriers which impact the enjoyment of various human rights and the role of mothers of children with albinism as defenders and implementers of those rights.

Background

Albinism

Albinism is a relatively rare, noncontagious, genetically inherited group of conditions resulting in little to no pigmentation in the skin, hair, and eyes (Kromberg & Manga, 2018; Kromberg et al., 2020). The condition affects people worldwide regardless of ethnicity or gender. While several types exist, oculocutaneous albinism type 2 is the most visible and the most prevalent in sub-Saharan Africa (Kromberg et al., 2012). The health implications of albinism center on vulnerability to skin cancer which kills a significant number in developing countries where access to healthcare is precarious. Albinism often leads to vision impairment that requires assistive devices. Tanzania has a relatively high prevalence of albinism with a 2012 census citing 1 in 2,673 (the United Republic of Tanzania, 2014, 2016). This is likely an underestimation because of challenges to data gathering in rural areas and fear of self-reporting related to Tanzania's history of violent attacks against persons with albinism (de Groot et al., 2019; Lund & Roberts, 2018). Persons with albinism in Tanzania face stigma and discrimination in nearly all aspects of life (e.g., education, employment, healthcare, and marriage). They also face ritual attacks motivated by erroneous but widespread beliefs that the body parts of persons with albinism can be efficacious in bringing good luck or wealth. This has resulted in multiple cases of grave desecrations, trafficking, ritual rape, and other forms of harmful practices (UNGA [United Nations General Assembly], 2017a; Under the Same Sun, 2020). Women and children bear the burden of human rights violations arising from albinism (Reimer-Kirkham et al., 2020; UNGA [United Nations General Assembly], 2020).

Parents' Advocacy and Albinism

Parents of children with disabilities in developing countries, rural areas in particular, face multiple challenges, specifically in the area of socioeconomic rights. These rights encompass access to an adequate standard of living in order to attain an appropriate standard of health. (Carey et al., 2020; Tigere & Makhubele, 2019). In parts of Africa, parents of children with disabilities also face stigma and accusations of witchcraft and wrongdoing on the basis of the disability of their child (Reimer-Kirkham et al., 2020; Tigere & Makhubele, 2019).

Increasing evidence shows that early intervention and parent training programs, to support children with disabilities, improves parent's self-efficacy. Healthcare workers are then able to implement such training and improve parenting self-efficacy (Hohlfeld et al., 2018). A scoping review (Hohlfeld et al., 2018) found that such intervention in the case of children with neurodevelopmental disabilities had "numerous psychosocial benefits for parents, including an increase in parental empowerment, a decrease in parental stress and the improvement of parental self-efficacy" (p. 1).

Mothers of children with disabilities develop a unique skill amassed from navigating the barriers to social inclusion on behalf of their children (Carey et al., 2020; Runswick-Cole & Ryan, 2019). Their potential activism as ongoing and coordinated efforts – not merely temporary or individual – remains undervalued by society (Ryan & Runswick-Cole, 2008). A study by Lynch et al. (2014) on albinism in Malawi identified mothers of children with albinism as potential advocates to mitigate the effects of isolation that often flows from bearing and rearing children with albinism. Although the role of activist-mother could be dismissed as a by-product of a maternal instinct, this view does not factor the discrimination both "directly and by proxy" faced by mothers of children with disabilities (Ryan & Runswick-Cole, 2008, p. 202). The combined effect of discrimination based on gender and discrimination against persons with albinism, a little-understood disability, multiplies the barriers for women with albinism and for mothers of children with albinism (Ero, 2017; Reimer-Kirkham et al., 2020). The experience of such women and children must also be understood within the patriarchal norms that suppress many women in Tanzania (Imafidon, 2018; Nyangweso, & Olupona, 2020; Reimer-Kirkham et al., 2020).

Locating the Activism of Mothers Impacted by Albinism within an International Human Rights Framework

Human rights are entitlements inherent to each human being (UNGA, 1948). Corresponding to these rights are duties to promote, protect, and fulfil human rights, and the state is the primary duty-bearer in this regard (OHCHR, 1998; ACHPR [African Commission on Human and People's Rights], 1981). At the core of human rights, whether at the national or international level, is human development including the morals and ethics that facilitate that pursuit (Rukooko, 2002; Stanford Encyclopedia of Philosophy, 2019). These morals and ethics are undergirded by principles of justice and fairness often embedded in human cultural practices (Rukooko, 2002). It is for this reason that without the use of technical terms in human rights, human beings are able to articulate what may be described as human rights violations.

In international human rights law, on which this chapter bases its human rights discourse, and where, in the last decade, a significant increase in attention to the rights of persons with albinism in Africa is noted (UNGA, 1948; Reimer-Kirkham et al., 2019; UNGA, 2019), persons with albinism hold the same fundamental rights as any other individual or group. These include the rights to life, security of person, equality, and nondiscrimination irrespective of, inter alia, impairment and gender, the right to the highest attainable standard of health, and an adequate standard of living. There are also international conventions for specific groups such as the UN Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) and the UN Convention on the Rights of Persons with Disabilities (CRPD) with counterpart African Protocols (Maputo and Disability Protocols, respectively). Persons with albinism are a constituency of persons with disabilities, and as reports from the Independent Expert indicate, access to the CRPD protection framework is often granted to them on the basis of their visual impairment alone (UNGA, 2019). However, persons with albinism also face discrimination stemming from their unusual appearance, in particular their skin color (Mswela, 2018; Phatoli et al., 2015; UNGA, 2017b). This suggests that persons with albinism encounter multiple and intersecting discrimination. Multiple discrimination is a situation where a person can experience discrimination on two or more grounds, in the sense that discrimination is compounded or aggravated. Intersecting discrimination refers to a situation where several grounds for discrimination operate and interact with one another at the same time in such a way that they are inseparable (UNGA, 2017b).

The harmful practices faced by persons with albinism are defined as "persistent practices and forms of behaviour that are grounded in discrimination on the basis of, among other things, sex, gender and age, in addition to multiple and/or intersecting forms of discrimination that often involve violence and cause physical and/or psychological harm or suffering" (CEDAW & CRC [United Nations Convention on the Rights of the Child], 2014, p. 524). According to the CEDAW Committee, "the practice of prescribing sex with girls or women with albinism as a cure for HIV, ritual killings and attacks on persons with albinism, including women and girls, the use of their body parts for purposes of witchcraft, and the stigma and social exclusion suffered by mothers of children with albinism" constitute harmful practices (UNGA, 2017b, p.8).

The African Charter on Human and Peoples' Rights establishes a general obligation that state parties should put in place "special measures of protection" (ACHPR, 1981, p. 6) for persons with disabilities in articles 18(2) and 18(4). The African Disability Protocol reaffirms many of the core provisions of the CRPD (Appiagyei-Atua, 2017). In addition, the protocol explicitly recognizes persons with albinism as persons falling under the scope of the protocol. It also has an expanded section on harmful practices which is among the key aspects distinguishing it from the CRPD. The CRPD and the protocol stipulate support for persons with disabilities, and their family members, as a cross-cutting principle directly linked to the realization of their rights and the general obligation of the state to carry out specific measures (UNGA, 2016).

Human Rights Defenders

Article 1 of the Declaration on the Right and Responsibility of Individuals, Groups and Organs of Society to Promote and Protect Universally Recognized Human Rights and Fundamental Freedoms (also known as the "Declaration on Human Rights Defenders") states that "everyone has the right, individually and in association with others, to promote and to strive for the protection and realization of human rights and fundamental freedoms at the national and international levels" (OHCHR, 1998, para. 9). However, doing so in non-orthodox ways, for instance, through narratives, storytelling, and support groups, means that these groups using non-orthodox approaches are not often recognized, supported, and protected as human rights defenders (Child Rights Connect, 2020).

According to the Office of the High Commissioner for Human Rights (OHCHR) (2020), human rights defenders are best identified by the work they do and the contexts in which they work. They often serve particular groups, such as women or children, and participate in activities that may not overtly be labeled as human rights, but which, in reality, contribute to the realization of international human rights standards (ACHPR, 2015; Rukooko, 2002). The three minimum standards of a human rights defender include (i) the advancement of human rights; (ii) the acceptance of the universality of human rights, meaning, they shall not promote human rights in a way that contradicts human rights or promote human rights in a discriminatory manner; and (iii) they ought to use peaceful means for attaining their goals (OHCHR, 2020). These three elements are found in the activism of the mothers who are the subject of this case study and who often take on the role of defending and realizing the human rights of their children with albinism.

Extending the Disabilities Discourse: Lessons from Fieldwork

In the remainder of the chapter, we extend existing disabilities and human rights discourse by drawing on lessons from Tanzanian fieldwork that illuminate how parents (mothers in this case; pseudonyms applied) become human rights activists to protect and realize the human rights of their children with albinism.

Describing the Study

In the context of a critical ethnographic study exploring the resilience of mothers impacted by albinism, at the intersection of gender and religion, we recruited participants through convenience and purposeful sampling by collaborating with a local nongovernmental organization (NGO) and other local and international key stakeholders from both urban and rural experiences in Tanzania. During two field visits, ethnographic data collection consisted of sharing circles (akin to focus groups), conducting in-depth semi-structured interviews and participant observation. Sixty-two participants were recruited: 26 mothers impacted by albinism and 36 key stakeholders (see Table 1). We conducted fieldwork with three Mamas' Groups (one urban, two rural) comprised of women impacted by albinism, whether as persons with albinism or as mothers of children with albinism.

Qualitative methods of data analysis facilitated by NVivo™ led to a final coherent analytic narrative (for detailed description of study methodology, see Reimer-Kirkham et al. (2020) and project blog at http://www.motheringandalbinism.com). Research ethics clearance was granted from the university in Canada, Tanzania's National Institute of Medical Research (NIMR), and the Tanzania Commission for Science and Technology (COSTECH).

Firsthand Accounts of Human Rights Violations and the Activism of Mothers of Children with Albinism

Based on information gathered in 2014 and 2019, the core human rights issues faced by women and children impacted by albinism globally are characterized by the following elements: blame and abandonment after having a child with albinism; increasing poverty; health risk for women and children with albinism; sexual violence for women with albinism; heightened vulnerability to attacks; impunity in context of access to justice; reprisals; and displacement (UNGA, 2020). The current study confirms the relevance of these elements and reveals some nuances, such as a general deprioritization of those elements that are related to attacks. The study highlights elements facilitative of social inclusion, particularly attitudinal change and socioeconomic rights. Importantly, it shows that mothers engage in human rights activism even when the technical language of human rights is not explicitly stated. The Mamas' Groups allow a consolidation of experiences – whether urban/rural and despite economic and educational differences – from which patterns of human rights violations are traced below.

Table 1 Demographic data

Mothers (N = 26)	
Mothers of children with albinism	9
Mothers with albinism themselves	17
Rural	14
Urban	12
History of intimate partner violence	15
Employment status	
Collective income (e.g., mamas' groups)	12
Subsistence income (e.g., selling fruit, milling grain, sewing, soap making)	1
Collective and subsistence income	8
Employment income	3
Retired	2
Religious affiliation	
Christian (incl. Catholic, Protestant, etc.)	19
Muslim	7
African traditional religions (ATR)	0[*]
Other/none	0
Key stakeholders (N = 36)	
With albinism	4
Without albinism	32
Occupation	
Educator	5
Nurse	4
Social worker	1
Journalist	1
Policy maker	1
Academic researcher	1
NGO/CSO staff	4
Faith leader	17
Missionary/volunteer	2
Gender	
Female	19
Male	17
Religion	
Christian (inc. Catholic, Protestant, etc.)	32
Muslim	3
African traditional religions (ATR)	0[*]
Other/none	1
Total participants (N = 62)	

[a] While no participants identified ATR as prime religion, there was evidence of how ATR overlaps with mainstream religion in participant interviews and observation

Poverty and the Intervention of Mamas' Groups

A lack of access to resources influences the day-to-day lives of the mothers. Many are already living in deprivation when they give birth to a child with albinism, in turn, resulting in an extreme form of subsistence if abandoned. They refer to poverty as a barrier to independence, dignity, and the ability to access education for themselves and their children. After describing two instances of attempted kidnapping of their daughter, Amana explained their situation:

> If we have food for the day, fine. If we don't, fine, but the way we are in this dead end [situation] where...I can't even manage to look for a job that is a working job because I have to somehow be there for the child [for her safety]... We struggle a day at a time.

In the context of poverty and scarcity, Mamas' Groups are a place of generating income through various activities, such as the production of high-quality crafts that are sold at markets frequented by international tourists. Additionally, they engage in a micro-savings and micro-loan system accessible only to members of the group. These activities fulfill, in part, the socioeconomic rights of mothers of children with albinism who have been abandoned by their partner. As expressed by one mother, Margreth: "So now at least if you have. . .a job. . .which you earn an income you will help your kids rather than depending on the husband." Other women with albinism in the group voiced the same sentiment, adding that the group gave them purpose:

> [I am] so grateful because of the support and the encouragement I get from this group...every time I come. . . I get encouraged and more hopeful that I have a means to somehow meet the needs of my children and raise them better. (Sharing Circle Participant)

Russom remarked:

> ...the soap making...gets some money that helps me get my daughter going for the next day, and also income we get from this group somehow pushes it. Of course it's not enough... everybody [in my family] is still getting a share from this little income that I have.

Even with the support of Mamas' Groups and the subsequent economic advantage, Russom noted that there is still room for progress, stating that despite "economic empowerment. . .the support is still not sufficient because we still have routine needs." Russom's insight describes the various social determinants of health impacting her and her family along with the other mothers. These illustrate areas where government policy and action must meet the efforts of individuals, groups such as these Mamas' Groups, and the work of NGOs/civil society organizations (CSOs).

Mothers also recounted multiple ways in which they advocate for access to education and health services. They tend to be the ones taking initiative to ensure the child has access to healthcare such as dermatologists or vision specialists. Amani explained, "I was the one. . .to advocate for schooling, glasses. . .I was dealing with my children all alone and following up on everything."

Where the child is enrolled in school, mothers indicate their concern for reasonable accommodation. The teacher may be unaware of the child's vision impairment or may be unwilling or unable to make accommodations. Mothers also spoke about bullying from other children which interferes with the child's learning. Amana reflected on her daughters' experience in school: "So the [other] kids really stigmatize her. Sometimes she'll come home with no glasses, no shoes." Zainabu, a mother and NGO staff with albinism, described how a mother's advocacy and persistence can be the difference between a discouraged child abandoning school and an empowered child continuing their education:

> Our mom struggled to get us education. I remember other kids were like 'Oh, what kind are you?' They're just touching you. 'Oh, it's just like us, ya.' And when you are a kid you don't know anything. 'Oh, what is this, that is happening to me?' Then sometimes I tell my mom that I don't want to go to school... But our mom was very strong and encouraging...'No, you have to go to school.'

This experience is in contrast to a number of the mothers whose children with albinism have been sponsored by NGOs to attend boarding schools, where both their educational and health needs are met (e.g., sunscreen, mobile skin and vision assessments). Yet, even then, mothers described having to ration a bottle of sunscreen provided by an NGO (where only sponsored children are eligible for the free access to sunscreen):

> One of my children is sponsored...but the other two kids with albinism are not...I will maybe wait until [my sponsored daughter] gets two bottles of sunscreen. Then I will take one and share it with the kids [who are not sponsored]... This is an important issue for us [where] we have more than one kid with albinism and only one is being sponsored and the rest are not sponsored. (Imara)

The Mamas' Groups, along with NGO/CSO support, are avenues to a basic level of human rights attainment.

The Social Support of Mamas' Groups to Counter Attitudinal Barriers

More than an income-generating group, the productivity of the mothers diminishes the deep and multilayered attitudinal barriers faced by mothers of children with albinism. One common barrier centers on myths and name-calling. These often begin from the birth of the child with albinism. A nurse with albinism observed: "You know we have this myth and when you have a child with albinism there are so many myths; many, I mean they can tell [you] anything." Attitudes toward albinism were functionalist at their base, tying the dignity and acceptability of a person with albinism to what they can do and, in the absence of proof to the contrary, considers the person with albinism as inept and incapable of working. As Zahara explained, "So you see your dignity is shattered.... People will kind of dismiss you, 'after all she's nothing, she's just a woman with albinism with nothing to offer." Other attitudes revolve around questions of the womanhood of the woman with albinism especially around her ability to conceive and to be economically self-sufficient. Johari explained that "when you get pregnant having albinism, everyone could feel pity for you, everyone could say that 'who did this to her' as if you have no rights to have that pregnancy."

The mothers who do not have albinism face discrimination on the basis of the albinism of their child. Oyana referred to the frequent name-calling of *zeru zeru* (often translated as ghost "ghost" in Swahili):

> [The] other challenge is from the community. Most of the conversations and disagreements with people always go back to, 'Oh, you're like a *zeru zeru* because you have a child [that is] *zeru zeru.* You're treated like you're not a human being.

Atiena, an NGO staff member, further confirmed how having a child with albinism irreparably taints how the mother is often rejected by her spouse and the community at large:

> They're single mothers. And the rejection and the discrimination does not end with just one child. Even if they have other children without albinism the stigma is still there because they have a baby or a child with albinism in that family.

Several interviewees observed that public name-calling was decreasing compared to the time of their upbringing ten or more years ago. Oftentimes, this decline was attributed to public education – either at the individual or community levels by groups, such as NGOs/CSOs, and through the work of Mamas' Groups.

Mothers expressed knowledge of how to change negative stereotypes and attitudes from society toward their child with albinism. One of the means is through parental acceptance and love of the child:

> If parents, both father and mother, accept the child and treat and love them, the community loves them too. But if you show discrimination to your child then the community is learning from you and they discriminate more. (Penda)

At the societal level, social inclusion efforts done early are key, as Zahara explained:

> So you see when you raise a child in an environment that is not friendly to the society, they grow in that isolation. Then it is very hard for them to mingle with the community. So it has to start, the integration [in society] as early as you can.

The result is that the mothers have been equipped to raise awareness about albinism in their community. Imara noted that this action has reduced the teasing and name-calling in her community, such that her children with albinism are respected more than before. Even though several other Mamas' Group participants shared this sentiment of a decrease in name-calling, some pointed out the limits of their efforts because they, as one explained, "cannot perceive what someone is thinking in his or her own mind about [my] children."

The productivity of the mothers through their income-generating activities is also a concrete response to attitudinal barriers, based on functionalism and their ability to contribute to society. As explained by Russom:

> The society could not understand if [we], women with albinism can do anything. They did not believe that we can work or have a business. But from our [Mamas'] groups it seems that people will learn we can work, and can do a lot together with other people. So that's one of the things that society could learn.

Another added:

> The things we've been doing as a group has also earned us respect out there in the society because this group is a classic example that if you empower women, we are capable. And the things we make here are made by both persons with albinism and mamas who have children with albinism and make a very good indication [to society] that, 'yes they have albinism but, they are making fabulous stuff.' (Sharing Circle Participant)

The income-generating activity thus becomes an awareness-raising in itself which is a counter-narrative to existing misbeliefs and negative attitudes toward albinism. This indirect awareness-raising complements traditional modes of [direct] public education which can inadvertently create an us-versus-them framework, especially when the awareness-raising is done by persons impacted by albinism.

Mamas' Groups as Source of Support Against Gender-Based Violence

The abandonment of children with albinism by their mothers was frequently reported. One interviewee, a Catholic Priest in Dar es Salaam, explained:

> Because men, even having had a Christian marriage or civil marriage or even traditional marriage, where they [get] an albino in the family sometimes the men run away. Leaves the mother alone with the child or children depending who is the first to be delivered. The general impression from the people around to have an albino in the family is not a blessing.

Gender-based violence included attitudes toward marriage that do not culturally approve options for women who wish to leave their marriage. Imara explained that upon the birth of her second child with albinism:

> My husband beat me, saying 'You've not stopped cheating with that albino man up to now.' For me, I knew from deep within that this was my child, his child, I did not know what to do. I contemplated wanting to move out but where would I move out to? There's nobody else who's going to marry a woman with two kids, three kids and two who have albinism. So, I decided to stay for the sake of my children... [I am] single handedly raising my kids. So it's like I am married and not married at the same time.

In the face of gender-based violations from their spouses and the community, the Mamas' Group offers a psychosocial solution. The group is a place of safety where a mother can share her experiences and receive emotional support. As Atiena (NGO staff) reflected, "For those women who have been rejected already, they need to understand that they are not alone." The chairperson of the Mwanza region Mamas' Group, Russom, herself a mother of a daughter with albinism, further detailed the impact of these groups and their broader potential:

> [This] kind of group is a very big help and also it can function to other people and those outside. [If] we could gather other mamas to learn the things that we are doing, because it seems like when they are alone, not in a group, they feel like 'I have a big problem and I can't handle it by myself.' But when you come together, we get to know that we can manage things, that we can do things.

The group offers a critical mass which is important for the condition of albinism that is relatively uncommon. Safiyah explained that “It’s not like the previous [years]. You find yourself just one in your village. But now we can meet even five [with albinism] in the public transport.” The mothers drawing on their experience recognize that visibility can shift community attitudes.

The Mamas’ Group also provides informal and long-term counseling on how to deal with domestic and social challenges. Here, mothers have access to other mothers who have survived their current struggles and have as evidence, their thriving children with albinism. Having learned of the value and dignity of their child with albinism, mothers enter into conjugal relationships from a place of power, often on the condition of acceptance of their child with albinism by the potential spouse or partner. Mothers are also willing to walk away from such relationships, even when it is an opportunity to increase their income.

Mamas’ Group as Protection from Attacks and Harmful Practice

Even though Tanzania has witnessed a decline in reported attacks in the last 4 years, mothers indicated that they still lived with deep-seated fear of attack (UNGA, 2017c). The fear stemmed from both the lack of control of perpetrators and the ability of myths about albinism to morph. Rehema described the attack on her young son while she was not home. A man dressed as a woman wearing a *hijab* entered her home and cut off one of her son’s fingers and attempted to kidnap him. A neighbor recognized the child and was immediately suspicious of the person carrying him. Noticing the child’s bloodied hand and obvious distress, the neighbor whistled for help, and it was the community that prevented the rest of the violent crime. This violence was facilitated by the child’s own father and uncle who, per Rehema, had told her husband, to either leave or recognize:

> the money you have in your own house...why do you sleep hungry and work so hard when you have all the money in the world that you need in your house? If you take that one...and if you just cut a finger, you will be very rich.

Fear of attack in this context has concrete impact on the socioeconomic activities of the mothers. Amana and Imara both identified this as one of their biggest challenges as mothers of children with albinism. Both described occasions of attempted kidnapping that affirmed their fears for the safety and security of their children. Amana explained how she struggles to go to work because her daughter survived an attempted kidnapping as a young child and again recently while she was walking to school. As a result, Amana accompanies her daughter to school, waiting nearby until school is over and then walking her daughter home. For Imara, the perpetrator was a man lurking around her neighborhood looking for her home. Because of her own advocacy within her community, it was the neighbors who recognized the suspicious activity and called for help. Following a series of events that eventually brought the police to her home, Imara stated:

> So this forced me to stay home, I can’t go to work, just watch over my kids. That scared me. I stopped them from going to school. Because I couldn’t ensure their safety.

The Mamas' Groups further empowered mothers to take on the role of protectors of their child(ren), a role normally assumed by the father in a patriarchal society such as Tanzania. Hamida, a social worker, described the following example:

> Two weeks ago another mom called me to share 'there's a number that is calling and saying they are NGO-1 and they were checking on...the child.' The mom asked me, 'do you know that number? I asked NGO-1 if they knew [the number] and they started tracing. Meanwhile, I called the street leaders and told them to be on the lookout just in case someone has bad intentions. In a span of 10 minutes we knew the number was for NGO-2. The child had been seen at a vision clinic and they were inviting her for a follow up [visit]. [In any case], I told the mother, 'continue being vigilant. Take the child as we have confirmed it's a genuine [appointment].'

In Hamida's example, we see the ongoing vigilance and extra precaution warranted by mothers. The Mamas' Groups examined and validated danger that mothers perceived. However, the mothers also reported that physical attacks had generally reduced in recent years, attributed to increased awareness about albinism. NGO respondents, on the contrary, made more frequent references to attacks and physical aggression against persons with albinism. They also raised other examples of harmful practices that are less likely to be reported such as the expulsion of a mother with albinism by her community for being a "curse" or a father cutting, forcibly or without consent, the hair of their child or partner with albinism and selling it. Overall, mothers tended to focus less on thwarting an imminent threat of attack on themselves or on their children but on the removal of barriers to the enjoyment of those rights that facilitate social inclusion.

The Activism of Mamas as Implementers of Human Rights Recommendations

As mentioned earlier, the ultimate responsibility for the promotion, protection, and fulfilment of human rights belongs to the state. In reality, the state is often hindered in its duties by limited resources. Accordingly, the principle of progressive realization or minimum core obligations permits a gradual realization of rights, particularly those grouped as socioeconomic rights including the rights to health, education, and an adequate standard of living (ACHPR, n.d.; OHCHR, 2008).

In the case of women impacted by albinism, having faced years without concrete or sustained intervention from the state, the mothers appear to have taken on this role. They have, through the building of a movement of women impacted by albinism at the community level, "provided a solution to the questions that they were asking themselves" (Joyce). The Mamas' Groups became a collective source of human rights intervention as well as a consolidation of, and complement to, their individual interventions, both in the advancement of human rights for themselves and ultimately for their children. The mothers' interventions are congruent with recommendations made to their government by the UN and the African Union (AU) mechanisms, indicating that the Mamas' Groups are more than a mere social support group.

The Government of Tanzania has been urged via numerous general recommendations from the AU and the UN to incorporate albinism into public health initiatives such as maternal and family support, cancer prevention, and genetic counseling (African Committee of Experts on the Rights and Welfare of the Child, 2016; UNGA, 2013, 2017d). In addition, governments ought to provide access to income-generating activities, as well as access to education including all necessary accommodation and devices. Also, they have been urged to raise awareness on albinism among health professionals and to ensure nondiscrimination on the basis of disability and color. They also ought to provide women impacted by albinism with remedial support when violation ensued including rehabilitation services, in the form of medical, psychological, and socioeconomic support in regaining their livelihood.

In 2016, the Committee on the Elimination of Discrimination Against Women made direct recommendations to the government of Tanzania as follows:

> The Committee urges the State party to reinforce its measures to protect women and girls with albinism from all forms of violence and address the discrimination, stigmatization and social exclusion faced by them. In particular, it calls upon the State party to effectively investigate, prosecute and punish those responsible for such crimes, expand its awareness-raising efforts to combat superstitious beliefs that are detrimental to the well-being of women and girls with albinism and ensure that those women and girls have access, without discrimination or fear, to education, employment, health care and other basic services (CEDAW, 2016, p. 14).

With regard to women in general who are subjects of harmful practices and other gendered forms of discrimination, the CEDAW urged Tanzania:

> To expeditiously adopt, in line with article 5 (b) of the Convention, a comprehensive strategy to eliminate discriminatory stereotypes relating to the roles and responsibilities of women and men in society and in the family, as well as harmful practices that discriminate against women, and create an enabling and supportive environment for women to exercise their human rights. The strategy should include comprehensive education and awareness-raising programmes targeting women and men at all levels of society, with a particular focus on traditional leaders. The State party should also monitor and regularly assess the impact of its measures (CEDAW, 2016, pp. 5–6).

The Regional Action Plan (RAP), 2017–2021, on albinism in Africa includes a measure to promote programs targeting women impacted by albinism (Action on Albinism, 2017). Further, the RAP includes measures encapsulating various recommendations from human rights mechanisms at the UN and AU including awareness-raising, both generally and targeted to health professionals, measures to end harmful practice such as legislation, access to education, and reasonable accommodation (the RAP's online platform is http://www.actiononalbinism.org). According to the RAP platform, Tanzania has met the target on women impacted by albinism including through the Mamas' Group. This is the only indicator on which Tanzania has hit the maximum of 100 percent based on the metric used on the RAP platform. Based on the available data from the Mamas' Groups and reports on the RAP platform, there are sufficient indicators that the activism of Mamas' Groups – and not active government measures – has delivered this target (Action on Albinism, 2017).

Discussion

The activities of Mamas' Groups both implicitly and explicitly show a powerful understanding of their human rights and how these have been violated and the corresponding and effective interventions that are needed, acceptable, and sustainable in their context. The latter two factors in particular are elements that may not be entirely considered when NGOs or governments carry out similar activities. While the government is the ultimate duty bearer in removing barriers to the enjoyment of human rights of women impacted by albinism, the best interest of the child, the absence of immediate and concrete intervention from government, and the capacity of the Mamas' Group to resolve a significant portion of their immediate barriers to human rights ought to be considered in terms of advocacy strategies in the implementation of human rights.

This study supported what was previously reported that the intensity of human rights violations based on albinism is gendered. These violations are disproportionately borne by the mothers of children with albinism and women with albinism. In the context of conjugal relationships, the vulnerability to gender-based violence and abandonment appears to be more severe in women with albinism than mothers of children with albinism because in the latter, the reason for stigma, namely, albinism, pre-dates the marriage or relationship. Negative stereotypes that drive attitudinal barriers in response to albinism tend to be driven by functionalist presumptions whereby albinism and mothers of children with albinism are viewed as a null unit of production in the community. There is a need to include in awareness-raising against attitudinal barriers answers to the particular questions relevant to the community. Awareness-raising on science alone, which is often popular, is unlikely sufficient given the multiplicity of influences in the life of the average modern Tanzanian.

Socioeconomic productivity was the core of empowerment for women impacted by albinism. It is an appropriate response to several human rights issues including attitudinal barriers and an adequate standard of living. It provides a limited respite from abject poverty triggered by various forms of gender-based violence such as abandonment and violence from partners and other family and community members. It was socioeconomic activity that distinguished this group of Mamas from a mere support group. Yet, even the support afforded to the mothers by this group such as a conceptualization of their experiences, a critical mass, counseling, information about albinism including on health and education, as well as protection measures are conditions facilitative of the enjoyment of their human rights and ultimately actualize several recommendations made by human rights bodies to Tanzania.

While the sample in this study is relatively small, it ought to be considered in relation to the relatively small size of persons with albinism who make up less than

1% of persons with disabilities in Tanzania and other neighboring countries. Therefore, the impact of the sample or the Mamas' Group as a whole should not be underestimated. It is also important to note that the Mamas' Group had a head start with support from international actors. However, this alone does not account for the success of the mothers as evidenced from their own responses and advocacy roles.

Mamas' Groups with socioeconomic activities at their core could be replicated to other countries across the Africa region. The relevant targets in the RAP indicate that several contextual similarities exist on this issue which will facilitate transfer to other locations. For example, Mamas' Groups may be considered for replication in Malawi with its similar history of violence against persons with albinism, a significant number of which were perpetrated by parents and other family members of children with albinism (Parliament of Malawi, 2019).

Conclusion

Mamas' Groups illustrate that parent support groups of children with disabilities, in this case albinism, can be a locus, not merely of support to their children but of human rights activism. Based on the evidence, the mothers have met the three minimum standards of human rights defenders. They have (i) pursued the advancement of rights by conceptualizing human rights violations through a consolidation of experiences, (ii) accepted and promoted the universality of relevant human rights by identifying what ought to have been done, irrespective of their gender, or the disability of their children; and (iii) promoted the enjoyment of human rights for themselves and for their children through the peaceful means of socioeconomic projects that facilitate the removal of barriers to the enjoyment of human rights for themselves and for their children (OHCHR, 2020).

NGOs working in human rights and albinism, in particular, should ensure that they frequently check in with community groups such as Mamas' Groups to mutually assess approaches, priorities, and human rights advocacy strategies. States should actively seek out and support groups of parents of children with disabilities such as Mamas' Groups as important partners in their primary duty to ensure the promotion, protection, and realization of human rights of persons impacted by disability.

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Building Cities for All: Amplifying Advocacy, Access, and Equity in the Urban Century

77

Victor S. Pineda, Serida L. Catalano, and Elian Sorensen

Contents

Abstract

Urban planners in the late nineteenth and early twentieth centuries viewed disability as a deficit to cure or a blight to erase. As a result, the built environment in the twenty-first century excludes, marginalizes, and invalidates the lived experience and basic dignities of 550 million people with disabilities that live in cities or urban settlements.

This chapter centers its analysis on the too often overlooked linkage between urban planning misplaced notions of space, justice, and sociality and their repercussions in the genesis and evolving experience of disability advocacy. The latter, in turn, by responding to and resisting these notions, eventually transformed and reshaped them. After a brief overview of the early urban planners' conceptualization of space and sociality, the chapter displays historical examples from the late nineteenth and early twentieth centuries, thus illuminating the often neglected experiences of disability advocacy in urban policy, planning, and design. In doing so, the authors try to show how early advocates set into motion practices to remedy past failures of urban planning which altered the

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social and spatial reality of future generations. What emerges is a legacy of resistance that in the late twentieth century fundamentally transformed the social and spatial conceptions of liberty and justice for all.

Keywords

Disability history · Disability advocacy · Planning history · Social movements · Built environment · Institutionalization

Introduction

Dominant architectural and planning practices neglected or purposefully ignored the lived experiences of persons with disabilities. Planners over the years responded in various ways to disability: as a public health issue (Molina, 2006), a public threat (Schweik, 2010), an individual tragedy, a biological deformity (Bond, 1947), social depravity (Longmore, 1985), a moral deficiency, or an ethical duty to solve (Fishman, 1982). Planners have both ameliorated and aggravated the atrocious abuses faced by disabled people (Longmore & Umansky, 2001; Imrie, 1996), and although this history is discussed in disability studies, practitioners and planners have largely failed to notice the centrality of disability advocacy in the urban realm.

To be sure, with few exceptions of scholar-advocates (Dear & Wolch, 1987; Imrie, 1996; Gleeson, 1997, 2001), planning literature does little to explain the ways that the urban experience of disability is situated within the legal, social, spatial, medical, and ultimately urban transformations that influenced the history of planning. Urban planning is in short supply of disability advocacy and as a result has historically failed to see disability as anything other than a medical impairment. As such, the planning profession has to a great part failed to consider social and environmental solutions to address the experiences of people with disabilities. From this perspective, the understudied history of disability advocacy in American cities provides a critical lens from which to understand the development of political efforts seeking to reimagine the role of the built environment and its potential to enable, rather than disable.

Advocates fought to undo generations of harm perpetrated by urban planners who conceptualized disability as a medical abnormality, or social blight.

From Berkeley to Washington, D.C., advocates struggled to define and assert the right to the city for, by, and with disabled people. In April of 1977, a historic battle took place in San Francisco where advocates, organized alongside a range of other advocacy groups, staged a critical confrontation for social and spatial justice, with a fundamental right to be considered whole and equal members of the societies within which they lived.

San Francisco was only one of many battlegrounds on which disability rights advocates claimed and fought for their right to be seen, heard, and considered.

This chapter highlights the underexplored relationships between the practice of urban planning and the advocacy efforts of people with disabilities and their allies.

We contend that disability has historically served as a vehicle for planners to “plan out” functionally impaired and disabled bodies instead of planning them in.[1] Urban planning has long sought to exclude disabled people from the urban environment, marginalizing an enormous subset of the population and largely denying full citizenship to those with disabilities. So far, early urban planning has emerged as the practice of exercising physical and social controls for desired social outcomes. The chapter also discusses how urban planning injustices catalyzed and were transformed by disability advocacy and how the genesis and evolving experience of disability advocacy responded and resisted dominant notions of spatial and social justice eventually reshaping them. By surfacing historical examples from the late nineteenth and early twentieth centuries, early advocates set into motion practices to remedy past failures of urban planning and in doing so altered the social and spatial reality of future generations. So far, by linking multi-generational calls for social and spatial justice, this chapter eventually illuminates the critical yet too often overlooked histories of disability advocacy in urban policy, planning, and design. What emerges is a legacy of resistance that in the late twentieth century fundamentally transformed the social and spatial conceptions of liberty and justice for all.

This matters for discussions on disability advocacy for a few key reasons. First, the history of urban planning is integrally connected to health, disability, and impairment (Longmore, 1985; Longmore & Umansky, 2001). Thus disability advocacy has largely focused on repairing the harms of urban planning. Second, considering disability advocacy as an urban experience illuminates the enabling and disabling role of planning, highlights the socio-spatial dynamics of inclusion/exclusion, and clarifies the motivations of disability advocates to redefine and reclaim public space. Third, the urban experience of disability demonstrates the intersectional nature of the struggle to assert and define access in that the latter is related to not only disability but also race, class, gender, and ethnicity.

The following sections explore the connection between urban planning, disablement, and disability advocacy. The first section of this chapter offers a broad overview of the historical connections between disability and planning by focusing on a few turn-of-the-century planning figures and showing the context within which planners broadly perceived and responded to disability. The second section of this chapter demonstrates how disability advocacy responded to social exclusion and provides case studies of historical and contemporary disability activism to highlight the relationship between urban planning and disability advocacy. Disability advocacy is defined as any action that speaks with or in favor of, recommends, argues for, demands, supports, defends, or even pleads for or on behalf of the social and spatial justice for persons with disabilities. Disability advocacy as a result has, to a degree, succeeded in rewriting the way in which individuals with disabilities can define – and be defined by – society.

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[1] This work is meant as a preliminary introduction and as such draws from various sources, across various cities, during the formative years of the planning profession in the United States to the present time.

The Medical Model of Urban Planning

During the years 1850–1910, efforts by a handful of urban planning pioneers conceptualized and produced spatial structures of explicit exclusion for large swaths of the population including women, racial minorities, religious groups, immigrants, and the working poor, among others, and last but not least, they too often understudied people with disabilities.[2] Since that time, disability rights and social justice advocates have sought to challenge laws, mandates, plans, covenants, ordinances, and policies that enforce dominant social structures of exclusion and created a built environment that hides people with disabilities and other perceived deviants and/or marginalized identities from public view (Schweik, 2010).

Civic leaders and urban planners during this time viewed disability as a social blight that needed fixing and promoted idealized and romanticized cities: to them, displaying disability in the city signaled not only decay but also social and urban deformity.

Prominent British planner Ebenezer Howard responded to the challenges of urbanization by proposing an environmental determinist cure to the urban ills associated with disability, namely sickness, poverty, and moral depravity. His early and influential work on *Garden Cities* embraced normative ideals of rational order that exiled people with disabilities from urban life. He argued that people with significant impairments would benefit from the virtues that fresh air, sunlight, and open natural settings could offer. In doing so, however, he intended to sequester persons with disabilities away from the non-disabled, creating what Susan Schweik described as “the promise of disability-free boulevards” in urban areas (2009, 146).

Howard’s influential work advanced the notion that the city was no place for persons with impairments and, by doing so, set a trajectory for planners to follow. His Garden City was a radical departure from the status quo in urban planning and was envisioned “to raise the standard of health and comfort of all true workers of whatever grade,” a theme which underpinned the development of a whole range of model towns that sprang up in the nineteenth century. Howard’s 1898 conception of the Garden City involved a particular notion of health and the spatial layout of Howard’s radial city was based on his conception of disability. Howard fundamentally juxtaposed health to disability in his plans and his view of disability as illness, in conjunction with the limited range of planning interventions that were available at the time, relegated disability to the outer margins of urban life.

His plans called for displacing people with disabilities into protected and isolated spaces. In an attempt to provide a place for various marginalized groups, Howard spatialized the zones of care and he took a great effort to define disability categories and territorialize them on his map. As such, Howard’s Garden Cities had specified

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[2] We understand that there is considerable debate within the disability community on the usage of person-first versus identity-first language to describe the experience and identity of disability. For the purposes of this chapter, we have chosen to alternate between person-first and identity-first language, using both the terms *disabled people* and *people with disabilities* in our writing.

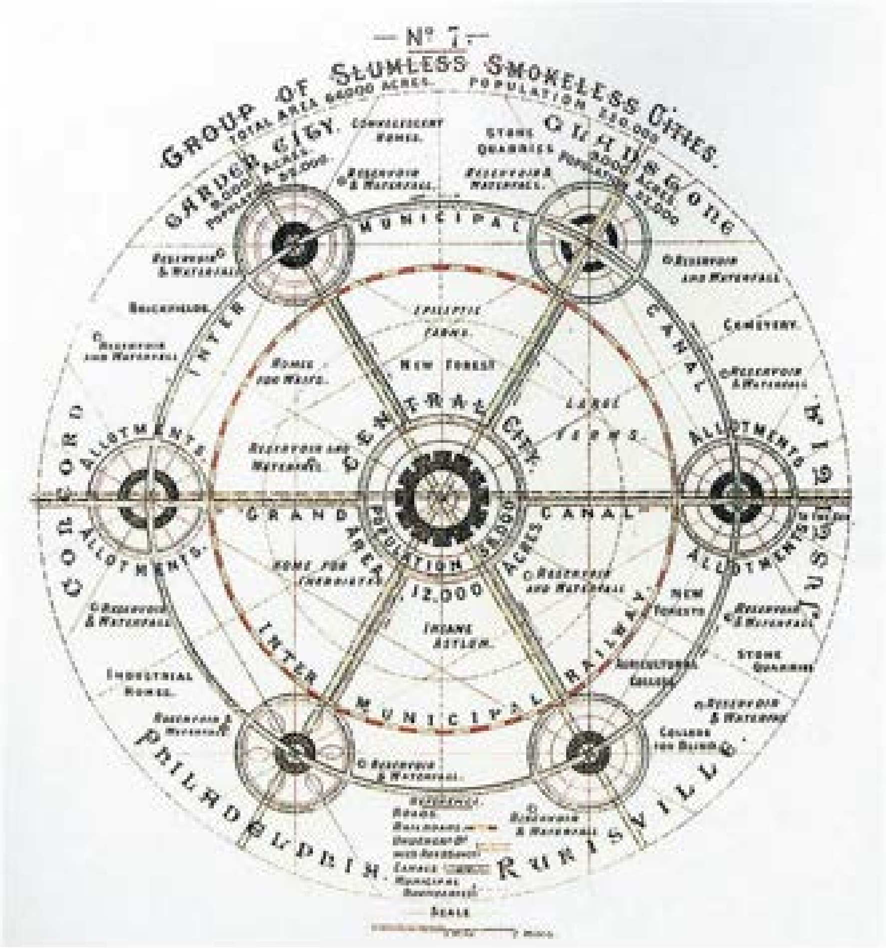

Fig. 1 Howard's Garden City (Howard 1902) planned for disability to exist outside of urban zones

spaces for inebriates, epileptics, lepers, the blind, and the insane (see Fig. 1). By zoning disability, and confining its existence into *spaces of care*, the Garden City rationalized, defined, and controlled the urban experience of disability. Howard thus consciously promoted a notion of spatial segregation of disability which is still dominant a century later in the United States (Wolch et al., 1988; Wolch & Dear, 1993; Dear & Taylor, 1982; Dear & Scott, 1981). Howard notes that "... dotted about the estate are seen various charitable and philanthropic institutions, in an open healthy district... [I]t is but just and right that the more helpless brethren should be able to enjoy the benefits of an experiment which is designed for humanity at large" (Howard 1902, 27). The "more helpless brethren" he was hoping to include in his social experiment embraced those who may not have then identified or been viewed as disabled. However, for all people with disabilities, such "benevolent" schemes are damaging.

Benevolent planning for disabled people (as with all other groups) perpetuates structures of social order and such orders are often reinforced by spatial segregation, institutionalization, and territorialized control. In Howard's seemingly well-intentioned plans, the helpless brethren, of whom persons with disabilities are a part, are pushed farther from sight. The contradictions between planners' intentions and the consequences of their designs are fundamental to the study of urban planning. These contradictions express the inherent tension between planning for and planning with targeted beneficiaries.

After Howard, spatial order and, more specifically, zoning became mainstays of the profession and were used by some planners as a reactive tool to compartmentalize and eliminate marginalized sections of society from parts of the city. To avoid creating a deformed city, planners helped to place human differences out of sight (Schweik 2007). Laws later developed that prohibited those with disabilities and diseases from appearing on public streets because of their displeasing appearance. According to Schweik, these laws reflected how society felt toward marginalized groups and demonstrated society's inability and unwillingness to incorporate human diversity into its perceived image of moral and bodily perfection.

Howard's plans for caring for the disabled in large open estates in part came to fruition in the United States through the architectural and planning efforts of Dr. Thomas Story Kirkbride. Kirkbride was a doctor and an architect who created "The Kirkbride Plan," a nineteenth-century building style that is the direct result of his influential book *On the Construction, Organization and General Arrangements of Hospitals for the Insane*. His book strongly influenced the development of a system of asylums throughout the United States. Kirkbride's plans and architectural designs for the construction, administration, placement, and maintenance of insane asylums did more to zone persons with disabilities out of urban life than any other single effort (Fig. 2) 1848 lithograph of the Kirkbride design of the Trenton Psychiatric Hospital, New Jersey Kirkbride if insane asylums.

Kirkbride Plan buildings were mostly large, imposing, Victorian-era institutions. They were between three and five stories tall, built on large extensively manicured grounds, which often included farmland. According to Yanni (2007, 151),

> A typical Kirkbride Plan building consists of a center section for the hospital administration and a living area for the superintendent and his family. Behind and to either side of the administration section are "wings" that contain patient wards. The patient wards staggered out and back from the administration section. From the air the building would look like a "V" or a "bat wing." Chapels, auditoriums, libraries, and kitchens were often built directly onto the rear of the administration section as this was a convenient, central location for these facilities since the male and female patients resided on opposite sides of the building.

The Kirkbride Plan layout was advantageous compared to previous building styles and was intended to facilitate care through a purposeful spatial distribution. The buildings enabled the arrangement of patients by type and gender, and the noisier and more uncontrollable patients were typically placed in the wards farthest

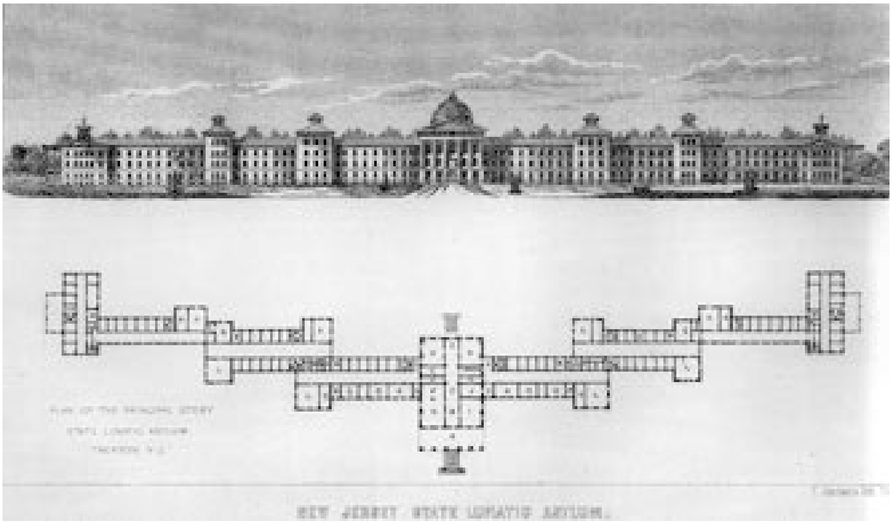

Fig. 2 Kirkbride if insane asylums

from the administration section. The design also allowed for easy expansion of the hospital; additional wards could be built onto the ends of the existing building without disrupting daily life at the hospital. By providing technical solutions to the spatial and functional administration of disability, the Kirkbride asylum was praised by city officials who sought to protect individuals from harm. Under the dominant theories of this time, this necessitated segregation and isolation as many believed that protecting people with disabilities required relocating them from their cities and communities into asylums. Because disability was a constant source of societal anxiety, progressive planners sought to “protect the disabled” by promoting special institutions and policies of institutionalization. These became the principal methods of dealing with disabled people.

Planners supported the institutionalization of persons with disabilities by promoting ordinances that would contribute to cleansing the city of impairments. Asylums for the deaf, dumb, and blind that once operated like local or regional charities were zoned through land grants and organized into federal and state institutions. Institutions received federal and state funds per patient, and thus asylums became a growth industry in the United States from 1850 to 1910. For planners this meant that their technical skills were in demand; put more directly, planners participated in building and zoning the architecture of exclusion. Cleansing the city of people with impairments was seen as a benevolent act that served the greater good *and* a business opportunity.

Immigrants arriving in large numbers also shaped the urban experience of disability. In many accounts, immigrants were seen as an illness or disease that had struck the city (Molina, 2006). According to Molina (2006), immigrants were often targeted as public health risks, a public burden, and dangerous. Immigrants who lived in poverty experienced social and spatial exclusion. Their confinement to a limited supply of affordable housing units promoted crowded conditions and increased the risks of disease transmission. The spatial concentration coupled with language barriers created a phenomenology of disability and social invalidity. Their diminished capacity to exercise individual agency in essence disabled them. Their deficiencies were in part due to the physical squalor and social stigma that limited their societal and functional utility relative to their local American counterparts.

The presence of disability in rapidly urbanizing cities such as New York, Chicago, Philadelphia, and San Francisco needs to be understood from multiple perspectives and with an awareness of the intersectional nature of many experiences. As has been argued, people with disabilities were seen as a burden, or even a threat, but this negative connotation was multiplied for disabled immigrant women, who faced triple discrimination and were vulnerable to exploitation and abuse on the independent facts that they were women, disabled, and immigrants.

Planners prescribed a variety of solutions to alleviate the city's perceived ills and mitigate the threat of contagion brought on by undesirables. Reforms and ordinances were seen as medicine for the disabled city, medicine that targeted the ill, weak, or infirm. Early planners sought to formalize the profession and emphasized the use of rationality and scientific inquiry as a key method for curing social ills. They argued that if science could cure disease, epidemics, and disability, so could urban planners. To them, planners were doctors, capable of healing abandoned, deformed, and unsightly spaces. Early planning studies based on science appeared to have an impact. By the 1860s, quasi-scientific studies commissioned by city managers in - New York, Chicago, and Philadelphia demonstrated the need for radical changes in health and sanitation. A new brand of "urban" science allowed planners to usher in key sewer and sanitary reforms (from 1840 to the 1890s), tenement reforms (1867), and strict immigration laws (1882).

The perceived impact of these laws buoyed the budding profession of city planning and endowed those who practiced it with an increasingly important social role. The laws contributed to controlling the spread of illness, and through sanitary reforms, these legislative efforts curbed the disabling effects of the disease. However, these laws also controlled and contained people, limiting their ability to live amongst and alongside others. In many cases, laws limited and controlled the lives and choices of people with disabilities not because of any real threat to society, but because of the perception of disability. Conceptions of social Darwinism influenced concerns that there existed a strong relationship between physical and mental impairments and crime, unemployment, and other forms of social malaise. Such conceptions led to the view that disability was a threat to the modern urban order. Civic officials in large cities saw disability as incompatible with the physical, social, and institutional order that they were entrusted to ensure.

Notably, not all planners and thinkers held this perspective. Some civic leaders and progressive reformers took proactive steps to plan disability and diversity into the turn of the century American city, rather than planning it out. Mary Kingsbury Simkhovitch, a progressive social reformer and sociologist living in New York City, founded the Greenwich House as a community center supporting women, children, and immigrants, many of whom had disabilities.

She was also active in shaping the profession of planning as it took shape during the turn of the century. Simkhovitch argued that social and physical planning should not be separated from one another and she called for a holistic and more social approach to urban planning (Simkhovitch, 1926). Through her work in almshouses, she came to understand how the social and physical layout of the industrialized city negatively affected women, children, and disabled people. Simkhovitch and her allies worked on housing and city planning in New York City by advocating for more community facilities, services, and networks to help individuals, families, and communities meet their social needs and maximize their potential for neighborhood-scale development (Simkhovitch, 1938). Simkhovitch noted that child labor, infant and maternal mortality, occupational diseases, and industrial accidents are mitigated when physical and social planning occurs in tandem (Simkhovitch, 1917) and she addressed these social issues by providing social services. Simkhovitch proposed three basic tenets for city planning: the provision of social services, community centers to provide such services, and local community involvement (Simkhovitch, 1906). The three tenets she promoted would be heard decades later in New York City in the chants of disability rights protesters who advocated for equitable provision of social services, community centers for empowerment, and measures to increase the participation of people with disabilities in their own communities. For people with disabilities and other marginalized groups, Simkhovitch's ideas ushered in new approaches that brought the targeted beneficiaries to the table.

Disability Rights and Advocacy and the Urban Revolution

The previous sections argue that the planning profession has largely sought to create urban spaces that exclude the needs of individuals living with disabilities, marginalizing an enormous subset of the population and largely denying full citizenship to those with disabilities. Advocacy efforts, to a large degree, have resisted these efforts by establishing and strengthening platform for inclusion and have largely focused on combating exclusionary environments in order to realize the goals of access, equity, and inclusion.

Through a set of interventions, advocates in Berkeley during the 1970s responded to the failure of urban planners to plan for disability and played a significant role in altering the practice of planning to better address the needs of disabled people.

Acknowledging the failures of urban planners to successfully plan *for* those with disabilities, and understanding the role of disability advocacy in addressing these shortcomings, they challenged planners, designers, and city leaders to change course thus bringing about dramatic ramifications for the future of cities.

As a response to the medical model of urban planning, disability advocates in the early 1970s emphasized the enabling and disabling roles of environmental design and raised the possibility of constructing more flexible, sustainable, and just cities. Disability advocates struggled to promote equality, social justice, social inclusion, and human rights for persons with any type of impairment and to eliminate social, physical, and institutional barriers to empower people and unlock their potential. In particular, they fought to show how disability is not simply a medical condition or an illness. As Rodas (2009, 837) argues, "[w]hen people speak of the social construction of disability, they refer to the view that disability is a social invention, a category determined not by the physical body but by external factors." Such external factors include social, physical, and/or institutional barriers that limit the freedoms of persons with disabilities to participate on an equal basis with others. According to this view, "while people with disabilities may be characterized by some form of physical impairment – blindness, deafness, or paraplegia – the physical condition of the body is secondary to the way that body is defined socially" (Rodas, 2009, 238). From this perspective, disability is "a product of the interaction between the individual and the environment" (Hahn, 2003). Thus, disability originates from a society whose design or attitudes discriminate against impairment, not simply from the physical composition of the body and/or cognitive structure of the brain.

When disability advocates talk about disability as a social construction, it becomes a social and spatial reality that cannot solely be tended to by medical professionals. It must rather be addressed by planners, policymakers, and designers who understand the nuances and diversity of the human condition.

The disability rights and independent living movements of the 1970s challenged policymakers, planners, and regular citizens to see disability as a broader social issue (rather than a private, medical one) that was shaped, in large part, due to the work of early urban planners. The movement addressed more than the elimination of physical barriers; it attacked the social and institutional barriers that continuously disable those with impairments. Within a greater social-civil rights agenda, disability activists in the 1970s coordinated social action with research, policy, institutional, and legislative changes to promote, protect, and ensure full and equal participation in the social, cultural, political, and economic aspects of civic life. It gave unprecedented access to the urban environment and dramatically boosted the quality of life of disabled individuals. Many other groups began to receive protections after the passage of the Americans with Disabilities Act: people living with cancer or HIV/AIDS, students with learning disabilities, and workers with invisible disabilities such as chronic pain, arthritis, and myalgic encephalomyelitis, otherwise known as chronic fatigue syndrome, just to name a few. This movement equated physical access to autonomy, mobility to freedom, and thus made the struggle for equal rights an inherently spatial struggle.

Based on planning theories of communal empowerment and organization, there was a strong desire to create a common activist front of the "grassroots disabled" that would eschew the historical divisions between disability groups and the traditional reliance on disability professionals to represent their needs. The remainder of this section provides case studies of disability advocacy in order to illuminate the relationship between urban planning and disability advocacy and further demonstrates how advocacy efforts responded to social and spatial exclusion.

The Disability Rights Movement of the 1970s originated at the University of California, Berkeley, where disabled students who called themselves the Rolling

Quads fought for equal access to education, public space, and independent living. The Rolling Quads aggressively lobbied the city of Berkeley to install curb cuts, going so far as to haul bags of concrete out in the middle of the night to build their own. They eventually shamed the city into creating the first community-wide curb cuts for wheelchair access and fought more broadly for the city to provide tools that would promote independent living and reduce functional barriers to independence. These early activists argued that isolation and segregation due to inaccessibility violated their civil rights and was perpetuated through exclusionary barriers developed by urban planners.

In April of 1977, disability rights advocates launched a series of protests and sit-ins across the country, fighting for regulations to make Section 504[3] of the Rehabilitation Act of 1973 legally enforceable. The most successful of these sit-ins was in San Francisco, where more than 150 disabled individuals and their supporters occupied a federal building for nearly a month, the longest sit-in in American history. Hundreds of their supporters gathered outside throughout the sit-in, and advocacy groups ranging from the Black Panther Party to the United Farm Workers provided material support and bolstered news coverage. These efforts were successful and the regulations were signed, articulating clearly to the American public that the consequences of disability were in fact the result of discriminatory beliefs and inaccessible environments and that the responsibility to repair these harms rests firmly on the shoulders of the government. It is difficult to overstate the significance of this message; the understanding that society is responsible for creating environments that work for everyone rapidly and dramatically changed the face of this country. Well before the passage of the Americans with Disability Act (ADA), Section 504 asserted that any federally funded institution must be accessible to individuals with disabilities, dramatically increasing access and inclusion nationwide.

In 1990, disability activists fighting for the passage of the Americans with Disabilities Act gathered on the National Mall, dropped their mobility aids, and crawled up the steps of the Capitol Building in what was later called the Capitol Crawl. These activists, following a tradition of disability advocacy dating back decades, understood that their disabilities were social and spatial realities, not simply medical impairments, and fought to demonstrate for the country the role of urban design in disabling them. That the Capitol Building, perhaps the most recognizable symbol of democracy in the world, was (and, to a lesser but not insignificant degree, still is) inaccessible illustrated the demands of disability activists for a country that had long ignored the urban experiences of people with disabilities. I. King Jordan, the first Deaf president of Gallaudet University who himself was put into office due

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[3] Section 504 is a federal law designed to protect the rights of individuals with disabilities in programs and activities that receive Federal financial assistance from the U.S. Department of Education (ED). Section 504 provides: “No otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.”

to disability advocacy efforts, argued then, “We’re not asking for any favors … we’re simply asking for the same rights and equality any other American has.”

Gallaudet University, the nation’s only liberal arts college for the Deaf, had for over a century only been run by hearing presidents. In 1988, following the decision of Gallaudet’s Board of Trustees to appoint yet another hearing president, students launched the Deaf President Now movement. These students and their supporters shut down the campus for a week, chaining themselves to the campus gates, holding sit-ins and media interviews, and shifting the public’s attention toward their demands. Eventually, the Board of Trustees relented and installed the first Deaf president of the University, I. King Jordan. The movement created the impetus for political representation and appreciation of Deaf culture in academia and beyond, shaping a larger advocacy climate at Gallaudet that later launched efforts to create a disability-inclusive built environment on campus.

In 2005, students, faculty, and others developed DeafSpace at Gallaudet, an architectural approach designed to center Deaf identity and experience. DeafSpace is both an acknowledgment of the cultural identity that has formed in response to adapting to the hearing world and a template for what the world would look like if Deaf people were never forced to make such adaptations. Its design elements are intended to make visual communication as unencumbered as possible and cover everything from the color of walls to the curvature of classrooms. Hansel Bauman, the campus architect of Gallaudet University who developed DeafSpace with their American Sign Language and Deaf Studies department notes that “DeafSpace architectural patterns are constructed when deaf people modify their environment to fit their linguistic, cognitive, and social sensibilities.” DeafSpace is a critical example of what the world could look like if the experiences of people with disabilities were centered. Notably, nothing about DeafSpace is inaccessible or difficult to navigate for hearing individuals, and moreover, DeafSpace’s emphasis on ramps, curving walls, and wide walkways benefit individuals with mobility disabilities as well. Gallaudet’s advocacy movements created the expectation that the beneficiaries of design and of instruction should also be the ones that shape them. This has repercussions for the greater world, far beyond Gallaudet University and the disability community, and ought to shape how urban planners and civic leaders develop, modify, and maintain the built environment.

The philosophies surrounding independent living, accessibility, and disability inclusion generally echoed the cries of emancipation, autonomy, freedom, and meaningful participation in much the same way as that of African Americans, Latinos, women, and LGBTQ individuals. What is significant is the manner in which this struggle became inherently spatialized connecting to it the imperative of access and the accessibility of space. The movement’s contributions to planning theory come from the manner in which it successfully equated physical access to autonomy and mobility to freedom. A renewed spirit of independence and hope resonated with our nation’s values. The ability of the movement to sustain the fight for over 35 years serves as a testament.

Disability advocacy in the latter part of the twentieth century effectively changed the face of cities, policies, laws, norms, and public spaces in the United States and around the world (Breslin et al., 2002). Some of the practical tenets brought up by disability-inclusive planning are already embodied in key laws protecting the rights of persons with disabilities. Key federal legislation such as the Architectural Barriers Act of 1968, the Rehabilitation Act of 1973, and the Americans with Disabilities Act of 1990 set into motion mandates, standards, and guidelines aimed at advancing employment and the public participation of persons with disabilities by incrementally removing physical barriers from the built environment. New standards in construction, transportation, and design were enforceable by laws. By identifying and mandating compliance with anti-discrimination law in education, employment, architecture, and transportation, these laws further empowered advocates in San Francisco, Chicago, Los Angeles, Houston, and Eugene, Oregon, to create pockets of radical inclusion that benefited not only disabled people but also older persons, families with children, and individuals with temporary or situational impairments.

Conclusion

The disability rights movement confronted and responded to outdated concepts and efforts of urban planners to cure, ignore, or erase the lived experience of disability. Advocacy through historical events described earlier (504 protests, the capital crawl, deaf president movement, and DeafSpace) form part of a larger and longer legacy and failures of urban planning. Ebenezer Howard, Kirkbride, and Mary Simkhovitch were early pioneers in thinking about disability in the built environment and responding to disability and difference in the way we design our cities.

Disability studies theorists have worked to broaden our understanding of disability and show that disability is situated and should be contextualized relative to environmental facilitators and barriers. Consequently, the identification of disability as a socio-spatial relationship sheds light on the socio-political role of planning. This chapter contends that an environmental approach to understanding disability helps us better understand social exclusion and marginalization in American cities.

The first section of this chapter explores how planners used their power to privilege some and marginalize others. Although not often acknowledged in planning history, it is evident that the work of early planners, such as Howard, Kirkbride, and Simkhovitch critically affected the lives of disabled people to a considerable degree. While their ideas of what disability was and how it should be responded to differ, their work influenced the profession in substantial ways. By exploring approaches to disability policy through the twentieth century, we can see the ways in which the dominant ideas of the time shaped the disabled individual’s prospects and outcomes. The dominant paradigms of this era perpetuated oppressive policies and resulted in the development and implementation of expensive plans with sometimes devastating results.

More often than not, urban planners shaped the urban experiences of persons with disabilities by creating spatial barriers, controlling access, territorializing disability, warehousing deformities, depriving agency, and containing deviance. Urban planners, city leaders, and others viewed people with disabilities as having little value in the modernizing state, and as a result, human difference was categorized, sanitized, and constrained. By interrogating the forces that shaped US cities in general, and US urban planning in particular, this chapter explores how our cities continue to disable and disempower their citizens.

The second section of this chapter illustrates how disability advocacy efforts have primarily focused on addressing the failures of urban planners by asserting the right of those with disabilities to access space, participate in city life, and otherwise hold equal citizenship. Though urban planners have largely remained silent about the multitude of quiet indignities and ghastly cruelties within their profession that galvanized the disability rights movement, the consequences of the profession's failures are no less clear.

The relationship between urban planning and disability advocacy elevates the need to document the profession's efforts to control and respond to bio-psycho-social diversity. This section provides case studies which explore this relationship and contends that the disability rights movement and the history of disability advocacy are a direct consequence of exclusionary planning efforts. Moreover, this section contends that the lived experience of disability parallels the common struggle to assert and define access and equity along dimensions of race, class, and gender. Disability has never been a singular or uniformed experience and continues to be highly differentiated by time and place, as well as by race, class, gender, and type of impairment. Specifically, the urban experience of disability illustrates the many ways prejudice is embedded in the physical and social construction of space.

Defining and claiming social and spatial justice continues well into the twenty-first century with vivid images and calls for equity and justice cropping up in cities across the country, persons of color, women, and immigrants alongside disabled people and their allies. There is now a turning point for more inclusive and human-centered approaches to urban planning.

Advocacy as a social practice constructs disability and illustrates the ways that advocacy has helped society evolve.

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Parent-Led Activism and Children with Disabilities in South Africa

78

Willene Holness

Contents

Abstract

Parents and caregivers of children with disabilities often act as representatives, mediators, and advocates for their children, partly out of necessity and partly due to the bias of adult-centered agency. This chapter engages with the literature on parent-led activism in South Africa. It also engages with broader activist campaigns which, due to their nature, sometimes subsume the voices of grassroots

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actors and the parents who tirelessly advocate for their children. The context of the use of advocacy and activist measures and an overview of the literature on parent and caregiver uptake of these is discussed identifying a critical loss of political voice of persons with disabilities post-democratic attainment as well as the need to build stronger child participation fora. The study finds that while the narrative of the social and human rights model approaches to disability dominates in mission statements and objectives of disabled persons' organizations (DPOs) and nongovernmental organizations, the services offered by some of these organizations have a definite medical slant. A brief synopsis of selected barriers that children with disabilities face, primarily in accessing their socioeconomic rights, including their right to education, health, and freedom from violence, is provided. Litigation brought by parents of children with disabilities is analyzed showing that professionals and organizations acting as curators ad litem and *amicus curia*, respectively, will likely continue to play an enhanced role in South Africa. Where parents and caregivers of children with disabilities are backed up by DPOs with traction in society, they are more likely to be successful in achieving their advocacy goals. Furthermore, the role of law clinics well versed in disability in representing these children, their parents, and DPOs is crucial. Recommendations for future law reform and activism is provided.

Keywords

Parents of children with disabilities · Activism · Litigation · Social justice · Disabled persons organizations

Introduction

Activism is conduct directed at bringing political and/or social change and in the disability context is a quest to secure social justice for persons with disabilities (Barnes & Mercer 2010). Activism by parents of children with disabilities seeks to challenge and dismantle the ableism present in different structures and systems that regulates the lives of their children. Parents and caregivers of children with disabilities often act as representatives, mediators, and advocates for their children, partly out of necessity and partly due to the bias of adult-centered agency (Wickenden & Elphick 2016). Yet, this role, particularly that of mothers, has been undervalued (Ryan & Runswick-Cole 2008). Bobel (2007) argues that the "activist" label is highly idealized requiring impossible standards of persistent and dogged relentlessness. This means that many persons pursing activist goals may not describe themselves as such. An advocacy–activist continuum denotes the move from parental advocacy for their children toward an activist stance. However, categorization of action as either activism or advocacy is problematic as parental interventions are fluid and goal-specific – and require using tools from either or both approaches (Poon-McBrayer & McBrayer 2014; Crow & Merchant 2019). Parental activism can be individual, collective, and may be informal or organized.

Many nongovernmental organizations (NGOs) in South Africa and disabled persons organizations (DPOs) find their origin in parental advocacy for their children with disabilities – such as the Disabled Children's Action Group (DICAG). A number of umbrella NGOs exist in South Africa, stratified along the lines of different disability identity groups (e.g., Autism SA, Blind SA, DeafSA, Down Syndrome SA, and Epilepsy SA). These NGOs sometimes have regional or local DPO members. Grassroots or local NGOs or DPOs, on the other hand, have members who include parents of children with disabilities. A key number of recent campaigns for realizing specific rights for persons with disabilities is a result of strategic advocacy and lobbying and litigation led by the umbrella NGOs that brief law clinics. Indeed, since the advent of democracy a small upsurge in Equality and High Court litigation dealing with the rights of persons with disabilities has occurred. It has focused on diverse issues such as scholar transport, wrongful life suits, reasonable accommodation in schools, sign language in schools, and compulsory incarceration of children "unfit" to stand trial.

This chapter engages with some of the limited literature on parent-led activism in South Africa. It also engages with broader activist campaigns which, due to their nature, sometimes subsume the voices of grassroots actors and the parents who tirelessly advocate for their children. However, it can also promote the voices of persons with disabilities, including children with disabilities, from the margins to forums such as domestic courts and treaty monitoring bodies (TMBs). The policy and legislative landscape, despite the lack of comprehensive disability-specific legislation, is relatively progressive. However, the flagship policy, the Department of Social Development's White Paper on the Rights of Persons with Disabilities (WPRPD) (2016), is not explicitly financed and mainstreaming disability across all sectors has faltered (Black & De Matos-Ala 2016). The efficacy of parental activism therefore can be undermined by inaccessible bureaucratic systems. However, it shows promise in many aspects for including children with disabilities and promoting their participation in life.

The context of the use of advocacy and activist measures and an overview of the literature on parent and caregiver uptake of these is discussed first. Then follows a brief synopsis of selected barriers that children with disabilities face, primarily in accessing their socioeconomic rights, including their right to education, health, and freedom from violence. Third, barriers to the daily activism of parents and carers in relation to children's schooling and access to services, including during the COVID-19 era, are outlined. Fourth, the role of parents and caregivers as protectors and advocates of their children's rights in relation to family responsibility for autistic children in the workplace and associational stigma experienced by mothers of children with albinism is identified. The potential role of anti-vax parents and caregivers as violators of their children's rights is identified as well as the ethical conundrum posed by wrongful life suits. Fifth, a brief reflective discussion on the literature follows considering parents and caregivers' role in partnership with DPOs and in litigation on behalf of their children, as well as the role of national human rights institutions in supporting children with disabilities. Finally, recommendations for future activism are provided.

Advocacy and Activism by Parents and Caregivers

This section first identifies the historical place of parental activism in South Africa. Second, the tools for activism such as lobbying for law reform, advocacy, and litigation are identified, as is the role of parents and caregivers in activism on behalf of their children. Third, the preference for child participation is discussed, and finally, the limited literature on parent-led activism in South Africa is analyzed.

Parent-Led Advocacy and Its Historical Roots in South Africa

Howell et al. (2006) documented the history of the disability rights movement in South Africa. This account, the authors concede, is limited due to the small number of participants interviewed and its emphasis on the origins of the formation of Disabled Persons South Africa (DPSA) – an umbrella organization that included membership from diverse disability groups. Their account includes a focus on the actions of adults with disabilities, as it reflects on how the international movement galvanized local movement toward organizing *by* persons with disabilities as opposed to organizing *for* them. Such paternalistic representation of persons with disabilities characterized NGOs prior to the 1980s. Mention is made of the self-help groups started by legendary activist Friday Mavuso in Soweto. Importantly, the formation and activities of DICAG are also discussed. The account reflects on how DICAG lobbied for the inclusion of children with disabilities on the agenda of the nascent democratic state, with notable successes such as the Disability Rights Charter. Post-1994, the organization promoted the disability mainstreaming agenda in policy reform.

According to Howell et al., DICAG provided a platform for parents to support each other, particularly as their shared experience of poverty and isolation in caring for children with disabilities came to the fore. More recently, DICAG has lobbied government for law reform in key areas such as education, health, and social development (DICAG 2008, 2016). Philpott and Muthukrishna (2019) identify that DICAG is embarking on a reflective strategic planning journey. However, documents indicating its future direction are not publicly available.

There are few organized parent advocacy groups in South Africa and most have been subsumed by larger NGOs and DPOs. For example, Autism SA was founded by parents and professionals aimed at lobbying and networking in 1989, while Down Syndrome SA was founded by parent advocates in 1986. Today, Autism SA has affiliate members (schools and NGOs focusing on autism), but not parent members. The nascent disability movement's roots can be traced in the literature on the history of the movement – including its successes in securing victories such as the inclusion of disability as a protected ground in the equality clause of the Constitution (Rowland 2004). Black and De Matos-Ala (2016) criticized the loss of critical voice and capacity when disability activists were subsumed into government, and also the more recent fragmentation of the disability sector. A focused narrative of the periods after the newly democratic state and negotiations by persons with disabilities and

DPOs for recognition in the new state machinery – aside from some reflections by Black and De Matos-Ala (2016) – is absent.

The Context of and Tools for Activism

Advocacy for the rights of children with disabilities often starts in the home and community. Stereotypes about the causes of disability and communities' perceptions about prognosis and ability to participate in community life can isolate and stifle the development and growth of children with disabilities in urban and rural areas. Traditional communities in rural areas face many challenges such as higher rates of poverty and incidence of gender-based violence (Cheteni et al. 2019). Children with disabilities in rural areas are doubly disadvantaged given the lack of access to resources. Community workers such as community health workers, child and youth care workers, and community disability workers are allies for families with children with disabilities and help in advocating for children's access to services, and for acceptance and inclusion in communities (Mahlangu et al. 2019; Lorenzo et al. 2012).

A move away from the central role that parents, especially mothers, play in advocating for their children, toward using a disability commons approach, has been called for in Britain. This is partly due to the perceived failures of mother-led activism (Runswick-Cole & Ryan 2019). Parental activism in relation to children with disabilities is fraught with contradictions. These contradictions emanate from the paternalism and medical approach that originally characterized parents' efforts to advocate for their children, and also from the move toward the social and human rights model approach to disability espoused by persons with disabilities from the 1980s onwards and which promotes self-representation (Carey et al. 2019). The possible disconnect between the goals of parents and disability activists should be acknowledged (Carey et al. 2021). This is particularly in South Africa where the charity/welfare or biomedical approaches still dominate the approaches to disability in many communities and state and private institutions (Howell, et al. 2006; Retief & Letšosa 2018; Mkabile & Swartz 2020a). This must also be seen in the context of a number of factors such as the burdens and challenges encountered by parents and caregivers, and coping strategies and support needs when caring for a child with a disability (Reddy et al. 2019; Tigere & Makhubele 2019; van der Mark et al. 2019; Maddocks et al. 2020; Sadiki & Kibirige 2020; Davids et al. 2021), and also the systemic barriers faced by children with disabilities generally and those with particular disabilities such as autism (Reddy et al. 2019). Accordingly, the role of the family in dismantling ableist stereotypes in communities cannot be denied (McConkey et al. 2016). However, the danger of children being neglected or abused by their parents or family members (Watermeyer and Mall 2016; Mdikana et al. 2018) weighs against the lack of safeguards where parents are their sole agents.

Parental abandonment, economic migration, the HIV/AIDS, and COVID-19 pandemics mean that in South Africa many children are cared for by relatives and non-relatives, and not their biological parents. This is particularly as they are more likely to be orphaned than their non-disabled peers (DSD, DWCPD & UNICEF, 2012). The triage protocol bias in favor of non-disabled persons during COVID-19 can have direct consequences where children or adults with disabilities do not receive adequate care, and indirectly when parents or caregivers die (McKinney et al. 2020). Accordingly, due to the structure of South African families and child care, it is necessary to consider parent and caregiver-led advocacy for children with disabilities.

Parents and caregivers' ability to advocate on behalf of their children depends largely on access to support and resources and whether their personal needs are met (Wright & Taylor 2014). In resource-poor settings, systemic failures can make their activism efforts appear futile. Poverty intersects with disability to create multiple barriers to accessing resources to secure rights (Hanass-Hancock & McKenzie 2017). Out-of-pocket expenses for persons with disabilities when seeking care and support, and access to services including health care and to enable participation in home and community activities, include high transport costs (Hanass-Hancock et al. 2017). Sousa (2016) argues that the cost of parental advocacy for children with disabilities is not generally measured. This cost refers to opportunity costs caused by efforts to correspond and obtain services for their children, which generally involves navigating intricate and inefficient bureaucratic systems. Not only are income-generating activities affected, but advocacy efforts also consume time that is needed for leisure, rest, and respite.

Parents use different strategies to agitate for change, from lobbying and advocating at an individual level where parents and caregivers advocate for their own children in particular situations usually at micro levels such as in schools and clinics, or at a macro or organizational level in peer support groups, parent groups and as part of NGOs or DPOs to obtain legal-political entitlements or law reform (Fengming 2016). Litigation is also used at times, initiated on behalf of a specific child or children, or more strategically as public interest litigation. In the United Kingdom, the disability movement increasingly uses litigation as a mobilization strategy, partly due to the change in framing of disability from a medical to a social model approach – which facilitated the birth of DPOs as opposed to organizations *for* persons with disabilities (Vanhala 2009). Self-advocacy of persons with disabilities has increased since there has been a move away from advocacy for such persons, toward activism *by* persons with disabilities in South Africa (Watermeyer et al. 2006). Kubicki et al. (2019) compare protest action as an advocacy tool staged on behalf of and brought by persons with disabilities in Poland, but similar scholarly attention has not occurred in democratic South Africa. Protests against the iniquities of apartheid measures undertaken by persons with disabilities is well documented (Rowland 2004). The use of social media to advance activist goals has been studied in relation to social movements (Loudon 2010) but not in relation to its use by parent activists. Increasingly, litigation is also used in South Africa to seek social justice. Meaningful enforcement of judgments obtained and compliance with and implementation of policy and legislative changes in favor of persons (including children) with disabilities remains patchy and inconsistent in South Africa (Boezaart 2012a; McKenzie et al. 2017; Kamga 2016b) and elsewhere (Winter 2003 referring to the USA; Aseka & Kanter 2014, referring to Kenya, for example).

Literature on the enforcement of litigation outcomes tends to focus on the roles of the main actors, usually DPOs or civil society organizations acting on behalf of children with disabilities or their caregivers – instead of the role of the parents in advocating for their children (Ngwena & Pretorius 2012; Du Plessis 2013; Holness, & Rule 2014; Holness 2016b; McKenzie et al. 2017). Others reflect on the responsibilities resting on the state to meet their obligations in respect of children with disabilities, such as protecting their sexual reproductive rights (Boezaart 2012b; Holness 2013) or obtaining perspectives of caregivers and parents on the rights of their children (Erasmus and Dada 2016; Huus et al. 2016) – including their sexuality (Kahonde et al. 2019). Chappell (2016b) noted the lack of political emphasis on the sexuality of adolescents with disabilities in South Africa.

The Child Participation Imperative

South African domestic legislation, in section 10 of the Children's Act 38 of 2005, promotes the participation of children in matters that affect them. This means that their views are to be garnered and considered when possible, considering their age, maturity, and stage of development. Their views are to be elicited, not only from family proceedings and medical decisions (Sloth-Nielsen, 2009). They should also be sought in all matters affecting children. Children and youth with disabilities are rarely included as participants in research about their lives (Walton, 2011; Donohue et al. 2014; Bantjes et al. 2015; Chappell 2016a; Dada et al. 2020). Their agency to self-advocate, however, is more restricted than children without disabilities, particularly where they have "stigmatised" disabilities such as severe intellectual, communication, or behavioral problems (Wickenden & Elphick 2016, p. 169), and where parents often act as their proxies. Child-friendly complaint mechanisms are rare and underutilized (Couzens 2012). For example, the South African Human Rights Commission's (SAHRC) recent child complaint procedures (SAHRC 2017a) are not yet tested. Generous standing provisions in South African law extend the ability to litigate not only to parents and associations acting on behalf of children with disabilities, but also to children (section 38 of the Constitution of the Republic of South Africa, 1996) (Budlender et al. 2014). The Equality Court's free complaint procedures are also underutilized by children or parents of children with disabilities (Holness & Rule 2014).

There are limited examples of attempts by children with disabilities to self-advocate for change – such as the students of Rivoni School for the Visually Impaired who protested against unsafe school facilities in 2019. Unfortunately, this action was not successful, and a national DPO continues to lobby the Department of Basic Education to make special school and hostel facilities safe (Pikoli 2020). Children with albinism participated in the National Conference on Albinism in 2013 and co-signed the Ekurhuleni Declaration on the Rights of Persons with

Albinism. Adults with albinism were more visible in participating in a round table on human rights and albinism which reached consensus on better participation of persons with albinism in future research and advocacy efforts (UN General Assembly 2019). Due to the environmental, physical, and social barriers posed to persons with disabilities seeking to protest a particular disability cause “in person” or physically, online activism can offer an alternative for those otherwise unable to participate (Li et al. 2018), or social media such as Twitter can be used to seek law reform (Auxier et al. 2019). Online activism by persons with disabilities in the Global South and South Africa has not received similar attention in the literature. Access to data pose barriers to using internet-based activism forums in South Africa.

Stereotypes about children’s ability and competence to express themselves and the accommodations that may be required to elicit their views influence the bias in favor of parental decision-making and agency. According to the United Nations’ (UN) Committee on the Rights of the Child, 2018, first prize is the participation of children with disabilities in decision-making – with requisite support where needed. In a training program for children with disabilities and their parents, the need for relevant support for the children to advocate and contribute to policy analysis affecting them was identified (Nomdo et al. 2011). Second prize is effective representation by parents and caregivers. The Committee (2018: para 12(d)) stresses that the role of parents, caregivers, and family members should be rendering support and empowerment to persons with disabilities “to have a voice and take full control of their own lives.” The roles of families and other stakeholders in obtaining the views of children about matters that affect them is crucial and the quality of the relationship with that child enhances obtaining their views (Knight & Oliver 2007). Effective representation by parent and caregivers is therefore a key concern.

Literature on Parent-Led Activism in South Africa

Literature on the positive outcomes of parent and caregiver-led advocacy in South Africa is rare. Scholars have noted the positive impact of caregiver advocacy in a particular locale, for example Orange Farm in Gauteng Province (Elphick et al. 2014; Elphick et al. 2015); and KwaZulu-Natal Province (Rule & Zuma 2011). Elphick et al. (2014) highlight the advocacy efforts and impact of 22 caregivers (mothers and grandmothers) of children with disabilities who are of compulsory school-going age. For example, one caregiver of a boy with hydrocephalus participates in human rights events where she makes public speeches, helps facilitate courses on disability and human rights, and participates in task teams with links to the department’s district office. Her role and other caregivers’ lobbying role in the task team helped with the building of a new school in the area for children with high educational support needs. The caregiver participants narrated challenges faced in accessing education for their children. These ranged from the cost and time involved in obtaining assessments, to the bureaucratic rigors involved in applying to multiple schools, the unsuitability of some schools due to harmful practices and discrimination against their children, and negotiations around high transport costs to schools.

The study identifies that caregivers are engaged in direct agency and also as proxy agents for their children. However, where multiple attempts at gaining ground on an issue failed, some caregivers had to resort to using the assistance of staff and resources from an NGO program that they had attended. Elphick et al. (2015) note:

> Programme staff were viewed as relatively more powerful. Complaints and follow-up referrals made by the NGO were perceived to get “taken seriously” (Caregiver). The Programme staff acted as proxy agents by utilising resources such as telephones, email, networks of professional contacts and transport to undertake activities on behalf of caregivers. These included emailing and calling, drafting letters of referral, taking children with disabilities and caregivers to meetings and assessments, advocating for school placement and arranging for host service providers in Orange Farm to undertake screening and assessment activities.

The study also identifies outcomes from the collective advocacy of the self-help group established by the caregivers. For example, the members participated in marches; launched a disability desk at a local police station; assisted a sexual abuse survivor with attendance at court hearings; contributed to a database of children requiring education in the area; and conducted educational workshops on disability in the community and elsewhere. The study also identifies how the group successfully lobbied for the school referred to earlier through activities such as letter writing to local government councilors, raising the issue in community forums and meetings with the department of education, and drafting written submissions to the mayor of the city and the parliamentary committee responsible for the implementation of the CRPD. Elphick et al. (2015) found that the caregivers relied on their faith, sharing knowledge and the collective agency of their self-help group to advocate for their children. The authors argue that stakeholders should create opportunities for self-help to enable caregiver advocacy as both direct and collective agents, as reliance on advocacy organizations as proxy agents is insufficient and discounts the contribution that caregivers can make to obtaining inclusion for their children.

In an earlier study, Elphick et al. (2014) discuss the barriers faced by children and their caregivers in the same locale. These include the experience of discrimination and attitudinal and environmental barriers. The study articulates that the caregivers’ strategies in dismantling attitudinal barriers, particularly experience of interpersonal (and especially family-based) stigma, were more successful than those used to seek access to essential services for their children. The authors identify that the caregivers incur intolerable personal and financial costs while advocating for their children. They seek recognition of the caregivers’ personal knowledge of the discrimination their children face and their personal investment as advocates for their children. Elphick et al. (2014. p. 251) propose that the caregivers’ agency should be supported through “empowerment programmes that incorporate elements of legal literacy, political participation, effective communication, self-advocacy, the formation of self-help groups and strategic alignment with other advocacy groups.” The authors also recommend the drafting of legislation to provide content to the socio-economic rights of children with disabilities, including provisions that punish non-compliant state officials.

Rule and Zuma (2011) explain the role that human rights forums, which include membership from parents and caregivers of children with disabilities, can play in a rural setting in KwaZulu-Natal Province. Constituted by the Office of the Premier of the province, these forums comprised 20 volunteer members from civil society, including widows and parents and traditional leaders. These forums received training on disability and the UN Convention on the Rights of Persons with Disabilities (CRPD) (United Nations' General Assembly, 2007) from an NGO. Preliminary results show an impact on parental activism in relation to interventions to address the high prevalence of sexual offences against children with disabilities in a particular community, and the vulnerability of girls with intellectual disability to the harmful, distorted cultural practice of *ukuthwala* (abduction and forced marriage) – for example.

Philpott and Muthukrishna (2019) critically analyze the parent–professional relationships in the early childhood education sector. Their study sought the views of parents and of staff members of DICAG. DICAG was established just before democracy was attained and has almost 4000 parent members and local branches in all provinces. Its focus is on advocacy and the monitoring of the implementation of state policy, as well as capacity building and parent empowerment. DICAG's membership of Disabled People International (DPI) and Inclusion International enables a larger footprint. The study considered how "parents of children with disabilities in a rural context experience and navigate partnerships." The authors found that while DICAG speaks to the human rights model and the agency of parents, in practice participants articulated their perceptions that "the agency and rights of parents are often ignored and infringed within partnerships." The authors found that the participants' view of professionals as "experts" and "gatekeepers" to access services and resources the children require was prevalent. As with other studies (Muthukrishna & Ebrahim 2014), the power imbalance between parents and professionals was identified. Philpott and Muthukrishna's study echoes Swartz's (2018) reflective essay on power imbalances in the disability sector – particularly where "experts" are involved such as professionals or researchers. The participants in Philpott and Muthukrishna's study articulate the corporate-managerial style of partnerships between parents and professionals, where service providers, including funders, seek to impose systems and ways of thinking instead of building capacity and learning from parents (or persons with disabilities) about their needs.

The authors' findings highlight the silencing and devaluing of parent voices and identify three key recommendations for dismantling neoliberal and medicalized discourses that view disability as the "problem" of the child and the parent. First, at an "individual level," participants identified a need for parental debriefing and counselling programs to allow safe spaces to support parents emotionally – lest "inappropriate expressions of emotions of grief, stress and anger. . .continue to negatively affect them and their parenting as their children grow older." They also echo other studies' findings that parental access to information to enable informed decision-making on behalf of their children is crucial (Sandy et al. 2013 (South Africa); Odongo 2018 (Kenya); Taderera & Hall 2017 (Namibia)). Second, at the "collective" level, Philpott and Muthukrishna support the collaboration of parents through peer-support groups and joint action. This recommendation underscores the role of so-called parental "self-help" groups. Third, at an "institutional and systemic" level, the authors promote parental representation in forums such as community and disability structures where relevant issues facing their children or constituency can be raised, and to ensure that professionals are held accountable. Ultimately, these structures exist in pockets and as the Orange Farm studies (Elphick et al. 2014, 2015) show, grass-roots activism can bring meaningful social justice change for the children and their parents. The proviso, of course, is that a "rights-based social justice agenda" should undergird the relationships between parents and professionals navigating the space of service provision to children with disabilities (Philpott & Muthukrishna 2019). The "pillar-to-post" experience that participants articulated in the DICAG study is a common refrain of a prevailing symptom of ineffective, incohesive, and fragmented social development services and legal aid provision in South Africa.

Carey et al. (2019) compared the approaches of organizations led by parents to DPOs in the USA. Their findings point to a diversity of approaches, including medicalization with the aim of finding a "cure" followed by some autism organizations, and medicalized support for the social model followed by some organizations for the blind and those with cerebral palsy, for example. In other words, parent-led activism does not fall neatly into the diametrically opposed social and medical approaches. It can include strategies to obtain access to services by using the medical approach in order to break down social barriers, for example.

When looking at the approaches followed by parent-led organizations in South Africa, the narrative of following the social and human rights model approaches to disability dominates in mission statements and objectives of organizations. However, the services offered by some of these organizations have a definite medical slant. For example, the National Council of and for Persons with Disabilities (NCPD), in existence for over 80 years, aims to "advocate and facilitate equitable social and economic inclusion of persons with disabilities in South Africa" in line with an espoused "rights-based approach within the framework of the social and human rights models of disability" (NCPD, 2021). In relation to children with disabilities, the organization aims to lobby government and collaborate with civil society to eliminate "barriers preventing social, educational, recreational and cultural inclusion of children with disabilities." One of its affiliate members, the Association for Persons with Physical Disabilities KwaZulu-Natal (APD-KZN), started in 1967 as "Natal Indian Cripple Care," supports preventing a physical disability (medical) approach in some instances and the social approach in others. For example, it offers assistance to obtain assistive devices, community-based rehabilitation, and assessments of children for placement in special or mainstream schools. It also offers protective workshops for adults with disabilities in nine areas across the province, and yet also claims to offer work placement "in the open labour market." This approach, according to Carey et al. (2019), would fall into the medicalized support for the social model category.

An overview of the contemporary context within which parents and caregivers advocate for their children's access to rights now follows. It highlights some of the pertinent issues facing children with disabilities.

Children with Disabilities Experience Barriers to Full Participation

The sites of struggle and the legal and policy framework within which parental advocacy and activism in South Africa takes place require exposition. Children with disabilities are entitled to a basket of socioeconomic rights, which the state is duty-bound to provide where parents and caregivers are unable to do so (Hansungule & Boezaart 2017). These rights are protected under the Constitution of the Republic of South Africa, 1996, under sections 26 (housing), 27 (health) and enabling legislation such as the Social Assistance Act 13 of 2004, National Health Act 61 of 2003, Mental Health Care Act 17 of 2002, and policies such as the Department of Social Development's WPRPWD and its implementation matrix. Child-specific rights are extended in section 28(1)(c) of the Constitution, which relates to the right to basic nutrition, shelter, basic health care services and social services. Unlike the section 26 and 27 formulations, the children's socioeconomic rights formulation is not subjected to the limitation of available resources and progressive realization internal limitations. Their immediate access to these rights and services in relation thereto are constitutionally guaranteed, particularly for those not in family care (such as those in state or alternative care) (*Centre for Child Law v MEC for Education, Gauteng* 2008).

The right to basic education in section 29(1)(a) is immediately realizable in South Africa (*Governing Body of the Juma Musjid Primary School v Essay NO* (*Centre for Child Law as amici curiae*), 2011; McConnachie & McConnachie 2012) and finds legislative enactment in the National Education Policy Act 27 of 1996 and the South African Schools Act 84 of 1996. The duty to provide reasonable accommodation in schools, including for children with disabilities, is judicially recognized (*MEC for Education: Kwazulu-Natal and Others v Pillay* 2008; *Oortman v St Thomas Aquinas Private School & Bernard Langton* 2010). Furthermore, the paramountcy of the best interests of the child standard and right is protected in section 28(1)(c) of the Constitution (Skelton 2019; Couzens 2019). A new policy document, the National Strategic Framework on Reasonable Accommodation for Persons with Disabilities 2020, developed to provide for reasonable accommodation measures in all sectors, including the education sector, has not yet been implemented as it still requires formal adoption by the National Economic Development and Labour Council (Nedlac), and the social dialogue forum in South Africa, before it is submitted for adoption in parliament. Such a cross-sectoral policy guideline may need legislative backing to police proper implementation and enforcement, particularly as the CRPD explicitly requires reasonable accommodations in all spheres.

The Promotion of Equality and Prohibition of Unfair Discrimination Act 3 of 2000 (the Equality Act) and Children's Act 38 of 2005, as well as the Criminal Law

(Sexual Offences and Related Matters) Amendment Act 32 of 2007 (SORMA), and the Child Justice Act 75 of 2008, all provide some provisions for children's access to justice in civil and criminal courts.

The Equality Courts, established under the Equality Act, have been underutilized by persons with disabilities to bring claims of unfair discrimination on the basis of disability. Two cases brought before the Equality Courts received mixed success. In *Oortman v St Thomas Acquinas Private School* 2010, a mother of a child with physical disabilities and a wheelchair user sought reasonable accommodation and accessible facilities in a private school. These measures were ordered, including disability sensitivity training for the teachers, but no monitoring of the court order has been noted. While mention of the court outcome is evident in the literature (Holness & Rule 2014; Khumalo & Fish Hodgson 2017), the mother and her child's perspective has not been sought after the litigation. In *Haskin v Khan* 2020, the mother of a child with cerebral palsy claimed, successfully, that a shop owner unfairly discriminated against her child when he refused access to him as his "buggy" (adapted wheelchair/perambulator) was banned from being used on his premises. The court order has not been enforced and the mother seeks to take the matter further to ensure compliance.

All the children's rights are enforceable in terms of the state's international and regional law obligations under the Organization of African Unity's (1990) African Charter on the Rights and Welfare of the Child; CRPD (UN General Assembly 2007); and the UN Convention on the Rights of the Child (United Nations' General Assembly 2019; Hansungule & Boezaart 2017). Time will tell how the provisions dealing with children's rights in the African Union's 2018 Protocol to the African Charter, signed by South Africa, but not yet in force, will be interpreted. Three TMBs, the Committee on the Rights of the Child in 2018, the Committee on the Rights of Persons with Disabilities in 2018, and the African Committee of Experts on the Rights and Welfare of the Child in 2019 – have called for state measures to ameliorate these gaps in service provision to children with disabilities in South Africa. However, despite the promise of the legal and policy framework advancing protection and respect for their rights, children with disabilities in South Africa face several barriers to their full participation, including accessing appropriate social, health and educational services (Human Rights Watch 2015; DSD, DWCPD & UNICEF 2012). The South African Law Reform Commission (SALRC) has embarked on a law reform process to domesticate the United Nations' Convention on the Rights of Persons with Disabilities (SALRC 2020). This may result in disability-specific legislation and/or amendments to existing discriminatory laws. In time, the extent of the SALRC's public consultation with children and parents and caregivers of children with disabilities will be revealed.

This next section identifies some selected areas of persistent systemic struggles that children with disabilities and their parents face, and which affect their ability to fully and meaningfully participate in all areas of life. These include challenges to accessing basic education, right to health, heightened risk of gender-based violence and inaccessible policing and justice systems.

The Right to Basic Education

The context of challenges to accessing this right is outlined. The section discusses several key court cases, such as a school admission case for a child with cerebral palsy and the proposed litigation to challenge the state's conduct regarding all out-of-school children with disabilities; a case dealing with access to basic necessities for children residing in an institution and with debilitating conduct disorders; a case about appropriate subsidization of schooling for children with severe and profound intellectual disabilities; a case about the use of sign language as a subject in schools for Deaf children; access to books, including Braille, for children who are blind or have print disabilities; scholar transport litigation; and finally a case dealing with access to personal protective equipment during the COVID-19 pandemic for children in special schools.

Massive Gaps in Educational Provision for Children with Disabilities

Realizing the right to basic education remains elusive for many children with disabilities. Unmonitored waiting lists to secure admission to schools with a high percentage of children being out of school, inadequately trained mainstream and special educators and inaccessible and unaccommodating teaching and learning environments, among others, remain as barriers to the education of children with disabilities – despite civil society advocacy to expose these challenges (The Right to Education of Children with Disabilities Alliance 2017; Section27 2015). This is despite a failed policy framework, the Education White Paper 6: Special Needs Education, 2001, that was aimed at meeting inclusive education targets by 2021 (Human Rights Watch 2018). The revised and Screening, Identification, Assessment and Support (SIAS) policy of 2014 has not yet been funded. The statutory provision for compulsory school-going age for children with disabilities has not been set, whereas the provision for children without disabilities has been in place since 1996 (sections 3(2) and (1) of the South African Schools Act of 1996). Parents who can afford assistive devices or classroom support such as facilitators as reasonable accommodation measures are able to secure places for their children in special schools, whereas children of those who cannot carry this financial burden are excluded from education (Right to Education of Children with Disabilities Alliance 2017). Parents' perspectives on barriers faced in securing inclusive education for their children have been sought (Swart et al. 2008).

TMBs are acutely aware of the education crisis facing children with disabilities in South Africa. The Committee on the Rights of Persons with Disabilities' (2018: para 12(c)) observed that:

> large numbers of children with disabilities, nearly 600,000, who are out of school or studying in specialized schools or classes, in particular children with psychosocial disabilities, and children with disabilities placed in centres for children or less regulated special service centres, all of which are based on long-term institutionalization, [are] often located far from their families and communities, isolated and lacking properly trained staff.

The Committee (2018: para 41(b) and (c)) recommended that the state allocates sufficient financial and human resources to reasonable accommodations of children with disabilities to receive inclusive and quality education in all schools, including in mainstream schools. The Committee pertinently mentioned children with intellectual disabilities, together with autism and Deaf children. The committee also recommended an effective training program for teachers on inclusive education, which should include learning sign language, Braille and Easy Read skills.

Admission to School

Parents seeking assistance to find school placement for their children from the Centre for Child Law have sometimes been successful on a case-by-case basis, yet systemic change is still illusive for most children with disabilities (Maistry 2018). Maistry explains that the nature of children's disabilities, particularly where they have high support needs, are often relied on as an excuse not to provide placement or resources so that these children can remain in school. A court victory was obtained for an 11-year-old child with cerebral palsy after a six-year struggle to admit him to a school (*IOL News* 2018). The Department of Education initially refused to provide him with the staffing needs to assist him at school after the special school he attended indicated it no longer had adequate staff. The court ordered his admission to a boarding school. Subsequently, the Department of Basic Education undertook to provide staff to assist him at school and in the hostel.

The National Council of Disabled Persons (NCDP), a DPO, cites inadequate state funding of educational centers for children with disabilities, including those who are of school-going age (NCPD, 2021). The NCDP, together with a number of other organizations (Autism SA and Down Syndrome SA), sought the assistance of the Centre for Child Law in bringing litigation to challenge the lack of provision of education for children with disabilities, and who remain out of school and on waiting lists (*IOL News* 2019). The COVID-19 pandemic overtook these events, and the matter has not yet been filed in court. This proposed litigation is an example of parent and caregivers forming alliances with DPOs to push for large-scale change in the implementation of the right to inclusive education, as parents of children were requested to provide relevant information on exclusion of their children from schools to the DPOs in preparation for its litigation.

Basic Necessities and Psychosocial Support for Children in Alternative Care

The need for a curator ad litem to be appointed for children with disabilities in litigation has arisen, not only in cases where their parents are not ideal to represent them – for example where they neglected their children – but also because of the expertise that these representatives can bring. For example, in *Centre for Child Law v MEC for Education & Others* (2008) a curator ad litem represented children placed in the alternative care of schools of industry which lacked basic care items such as bedding and psychological and social support services. The Centre for Child Law is a law clinic. The court identified that these schools of industries were subject to a higher duty of care than the children's parents.

Referring to this successful litigation, Boezaart and Skelton (2011) identify that children with debilitating conduct disorders are woefully treated and that curator representation can help force state provision for better models of care for these children. However, the authors also caution that strategic litigation may also be needed in the future to ensure that the needs of these children are met by the various stakeholders.

The challenges faced by children with disabilities who reside in residential institutions, including in communicating their needs, is underexplored (Geiger 2012). Parental and caregiver advocacy and activism on their behalf is also not generally studied.

Reasonable Measures, Including Financial, to Secure the Right to Basic Education

The case *Western Cape Forum for Intellectual Disability v Government of South Africa & Another*, 2011, illustrates the massive gaps in state policy on inclusive education, the lack of political will, and possibly the lack of expertise, to implement supervisory court decisions. The Western Cape Forum for Intellectual Disability (WCFID), an umbrella NGO, represented numerous special education centers, NGOs for the most part, which provide education and rehabilitation services to approximately 1000 children with severe and profound intellectual disabilities. The inadequate subsidizations of these education providers, according to the Department of Basic Education, were excusable because children with severe and profound intellectual disabilities were thought to be unable to benefit from education and were considered “ineducable.” While the state provided funding for and established special schools for children with moderate to mild intellectual disabilities, they did not admit children with severe and profound intellectual disabilities to any special or other state schools. Children unable to access the special care centers run by the NGOs are not educated. Approximately 500 children in the Western Cape Province alone were on the waiting list to be accommodated at special care centers at the time of the litigation. The Department of Health provided small subsidies to the NGOs. Ultimately the financial support offered to them was less than that the state provides for children without severe and profound intellectual disabilities.

The court found that “Inasmuch as the state currently cooperates with and relies on organisations such as the applicant to provide education for [intellectually] disabled children, it must be borne in mind that this does not relieve the state from its constitutional obligation” (para 24). The structural interdict issued by the court contained a declaration of rights violations (access to basic education, protection from neglect or degradation, equality, and human dignity). The court found that both the positive and negative dimensions of the children’s right to equality were infringed, as the state failed to provide these children with a basic education and did not admit them to schools. Furthermore, the court found that

> the children’s rights to dignity have been infringed since they have been marginalised and ignored and in effect stigmatised. The failure to provide the children with education places them at the risk of neglect for it means that they often have to be educated by parents who do

> not have the skills to do so and are already under strain. The inability of the children to develop to their own potential, however limited that may be, is a form of degradation. (para 45)

This finding must also be seen in the light of the state's contention made to the court that the parents would be responsible for teaching any skills to the children, as "no amount of education will be beneficial for them" (para 17). That contention was aptly disposed of by expert testimony and relevant international and comparative law which explicate the need to ensure that all children reach their full potential. The order also included an instruction that the state must take reasonable measures to ensure that all children in the province have "affordable access to a basic education of an adequate quality"; provide "adequate funds to organizations which provide education for severely and profoundly intellectually disabled children in the Western Cape at special care centres" toward "the use of adequate facilities"; and that there are "adequate staff," "appropriate transport," and "proper accreditation, training and remuneration" of staff. The Department had to report back to the court on the measures implemented (para 52).

This case garnered very substantial scholarly attention (Ngwena & Pretorius 2012; Ngwena 2013; Skelton 2013; Murungi 2015; Kruger 2015, Kamga, 2016b; Spangenberg et al. 2016; McKenzie et al. 2017, 2019; Wood et al. 2019). Ngwena and Pretorius (2012) are scathing in their analysis of the state's conduct that led to the widespread state neglect of these children. The state disregarded the White Paper 6 policy which was "manifestly intended to be inclusive," and instead relied on prejudicial tropes about the ineducability of these children, acting "without any moral compunction, [and categorised and drew] a distinction between what is 'normal' and deserving of a claim on state resources from what is 'abnormal' and undeserving" (Ngwena & Pretorius 2012, p. 114).

McKenzie et al. (2017) praise the intervention of WCFID as a community-based organization but warned that implementation of the court order would require continued advocacy and lobbying. Unfortunately, the court order, while progressive and potentially ground-breaking at the time, left it to the discretion of the government stakeholders, particularly the Department of Basic Education, to formulate interventions that meet the standard of "reasonableness" to address the shortcomings in educating these children. As a result, despite continued attempts by the litigants to consult with and lobby the state and advise on good practices for ensuring adequate provision of education-related services such as transport for the children and appropriate funding for infrastructure, staffing, and training – implementation has been slow, incomplete, and in some respects inadequate (WCFID 2019). These centers are still not offered direct funding by the Department of Basic Education. Instead, "transversal outreach teams" have been offered. The therapies proposed to be offered to children by the rehabilitation professionals in these teams have been inconsistent and infrequent. The Departments of Social Development and Health continue to subsidize these centers. This is a fact that the court did not approve of as the main responsibility for education by the state rests on the Department of Basic Education. The danger of unregulated education providers for children with disabilities, and particularly for children with severe and profound intellectual disabilities, remains.

Many of these centers provide so-called "stimulation" for these children, but this amounts to no more than basic caregiving activities and these children are not educated. Parents and caregivers often have no choice but to leave their children in the care of these centers – as there are few to no alternatives. The continued neglect of these children by the state, particularly in relation to accessing basic education, is a gross human rights violation. The voice of the parents and children involved in and affected by the litigation is missing. Wood et al. (2019) comment that the WCFID continues to advocate for proper implementation of the court order. McKenzie et al. (2019, p. 208) identify that the policies that have been developed on inclusive education and specifically the new policy on provision of education to these children do not align the "roles and requirements of educators and educational facilities" "to the needs of these children." Further, that the increased budgetary allocations (both human and infrastructural) remained invested in the segregated education system.

While the WCFID's continued lobbying for social justice for these children is commendable, scholarly attention is needed to measure the impact of the court order and subsequent policy and budget interventions on the affected children and their parents – with an emphasis on their perspectives.

Sign Language Provision in Schools

Language planning policy in relation to sign language was stagnant for many years after the advent of democracy (Reagan 2008). The language and culture rights violations of the Deaf caused by ethnolinguistic separate development during apartheid were perpetuated in democracy (Magongwa 2010). The settlement reached in the *Springate* case brought subsequent reforms in curriculum development of sign language as a subject in special schools (Holness, 2016b). However, the implementation of South African Sign Language (SASL) in schools was substantially delayed. The Deaf matriculant, Kyle Springate, brought the litigation in his own name, represented by the LRC. He was supported by his mother as a co-applicant, and the Deaf Federation of South Africa (DeafSA) an NGO, as well as by a number of schools. Both his and his mother's affidavits set out the challenges that he experienced in securing the offering of sign language as a language subject at his school (a mainstream school). DeafSA, in its papers before court, explicated how it had lobbied and advocated for sign language to be offered in schools for over 12 years.

A compromise was found for Kyle to allow him to matriculate through a court settlement, but the public interest goal of sign language as a subject offering would have to wait. The *Curriculum and Assessment Policy Statement* for South African Sign Language was approved by government gazette in August 2014, in terms of the National Education Policy Act 27 of 1996. A long period of curriculum development ensued, which at the outset only had one Deaf representative on the oversight body. Since 2015, SASL has been offered as a home language subject in special schools, initially for the early grades and by 2018 for matriculants. Non-fluent sign language teachers, however, continue to create barriers to SASL proficiency and the lack of SASL acquisition in the home means that children struggle to learn SASL while also learning other subjects in schools (Ngobeni et al. 2020).

The *Springate* case, which galvanized years of inaction into reality for using SASL, was effectively brought by a mother and her Deaf child. Their voices were articulated in the pleadings before the court. Importantly, they were supported by DeafSA and a number of schools for the Deaf. The litigation was not brought on the usual strategic impact planning basis that underlies some of the education-related cases that expose systemic challenges in South Africa. Nonetheless, its impact has been far-ranging. Yet, implementation of the policy to develop SASL as a language in schools has been fragmented – with a lack of curriculum resources and inadequate training of teachers detracting from the legal and policy victory (DeafSA 2018).

Access to Learning Materials, Including Books

Access to learning materials and infrastructure such as safe buildings is a barrier for children with and without disabilities. Where decades' long lobbying and advocacy fails, litigation is often the only answer. Yet the gains from the litigation are countered by delays and a lack of political will in implementing the court orders. For example, the "mud schools" debacle where there was a lack of infrastructural development of schools despite the first court victory in 2011 (Skelton, 2018) and a more recent one in 2018 which forced the Department of Basic Education to draft compliant regulations on school infrastructure (*Equal Education and Another v Minister of Basic Education* 2018). Another apt example is the Limpopo textbook trilogy of cases, culminating in the *Minister of Basic Education v Basic Education for All* case, where the attorneys for the students and their representatives widely published the judgments obtained in their favor with a view to gathering information from parents and students on the implementation of the order at schools – in other words as a way of monitoring the enforcement (Veriava 2016). The synergy between advocacy and the shrewd choice of litigation techniques used by the law clinic that represented the applicants was vital. In the first case, a law clinic had to act as an applicant due to intimidation suffered by schools that wished to participate in the litigation. The court accepted the standing of a mother of two children from one of the schools affected by the non-delivery of textbooks as a co-applicant due to her "material interest" in the matter (*Section27 and Others v Minister of Education* 2012). By the time the third case arose, a community organization, Basic Education for All and a number of schools took up the cudgels on behalf of affected children in the province (*Minister of Basic Education v Basic Education for All* 2016).

Two cases brought by DPOs for persons with visual or print disabilities should be mentioned. First, following on the partial success of the litigation in the Limpopo textbook case, the South African National Council for the Blind, together with the South African Braille Authority and three schools for students with visual disabilities, sought to have learning materials, primarily textbooks, made available to children in Braille. A settlement agreement was reached with the state after 6 years of engagement and lobbying on the issue (Section27, 2018). Second, a lobbying campaign in favor of passing the Copyright Amendment Act, which would see copyright laws change to allow Braille and extend fair use to teachers and students, was launched by a number of NGOs and DPOs – including BlindSA, ReCreateSA, the South African Disability Alliance, South African Braille Authority, SAGA, Right2Know, A2K, Sadtu, and Section27.

Following the campaign, a court bid was issued recently in the Gauteng High Court contending that a “book famine” for persons with visual impairments is caused by provisions of the current copyright legislation. The contention is that the legislation unconstitutionally prevents persons with visual impairments from accessing books subject to copyright and does not contain exemptions as contemplated by the Marrakesh Treaty to allow such access (*Blind SA v Minister of Trade, Industry and Competition & Others*, 2021). Blind SA, a disabled persons organization, considers these limitations as violations of the rights to equality, dignity, freedom of expression, basic and further education, and the right to participate in the cultural life of choice for persons with visual and print disabilities. Neither the voices of children with visual and print disabilities nor their parents as their representatives are showcased by the campaign or the court case.

With the COVID-19 pandemic illustrating the acute need for cheap and free access to data to enable education to take place remotely where needed, the huge inequalities between those that can afford internet access and those who cannot are likely to become a crucial political tool.

Transport to Schools

Transport provision for school children with disabilities is dismal nation-wide. In 2011, a settlement agreement which was made an order of court was granted in the North West Province. Here parents and caregivers of 36 children sought appropriate scholar transport provision for children residing in a rural area. They were from impoverished households and relied primarily on social grants (*Adam Legoale v MEC for Education, North West* (2011) cited in Skelton 2013). The parents and an NGO, the Centre for Child Law, represented by the LRC, obtained a court order that parents and caregivers were to be provided with a detailed plan of the proposed transport provision.

In a settlement agreement by consent in KwaZulu-Natal Province, the High Court ordered that the provincial department of Education draft and implement a transport policy for children in the province (*Equal Education v MEC for Education* 2017). Section27 represented Siphisila Isizwe, a DPO located in rural Manguzi in Umkhanyakude District. The DPO acted as an *amicus curia* and intervened to highlight the transport needs of children with disabilities. As a result, the court order required a plan for the transport of children with disabilities to be included in the policy. It took 3 years for the policy to be drafted and unfortunately excluded a number of universal design aspects and excluded children with disabilities in mainstream schools (Section27, 2020). This litigation was brought after a three-year campaign by the NGO Equal Education. This resulted in a national transport policy being drafted which delegates transport provision responsibility for children with disabilities to provincial departments. The model of Equal Education, which puts children at the forefront of activism as so-called “equalizers” involved in information sharing, protests, and litigation for its campaigns, should be replicated by DPOs and parents of children with disabilities.

Affect of COVID-19 on Schooling for Children with Disabilities

The return to school for children with disabilities when lockdown restrictions were eased was in a state of uncertainty. A number of NGOs and DPOs lobbied government to ensure that the health and safety measures required for children with disabilities as they returned to schools and hostels and special care centers would be met, as well as the educational and therapeutic needs of those remaining at home – including the provision of assistive devices. These measures included the provision of personal protective equipment (PPE) to children and staff. Due to the delayed responses from the Department of Education, the Centre for Child Law, represented by the Equal Education Law Clinic, brought an urgent application in the Gauteng High Court in July 2020. It challenged the failure to provide the necessary support measures to children with disabilities. A court order by consent was issued, requiring the Department of Education to revise its directions, guidelines, and standard operating procedures – in line with the access to education imperatives (Hasungule 2020; Equal Education 2020).

The school nutrition case, *Equal Education & Others v Minister of Basic Education & Others*, 2021, sought to obtain relief for nine million children whose access to nutrition at schools was affected by school closures at the start of the COVID-19 pandemic and subsequent thereto. The impact of the break in provision of school nutrition to children with disabilities should be studied. Beckmann and Reyneke (2021) suggest better inclusive constructive stakeholder consultation by principals of schools of children with severe and profound intellectual disabilities and parents to better serve the educational needs of these children at a time when government COVID-19 regulations severely constrained their access to education.

Early childhood education and development (ECD) is not guaranteed for children with disabilities in practice, despite the value it brings to inclusion of children, and its mitigating effect when early interventions are provided in the early years (Philpott 2014). The value of ECD for child development was illustrated when centers closed during the COVID-19 lockdown periods in South Africa and elsewhere, with their devastating consequences for family poverty, food insecurity, bereavement, decreased access to health care – including access to vaccinations (Yoshikawa et al. 2020; Abbas et al. 2020).

Disruptions to education for children with disabilities occurred, including in special schools, and it became clear that remote learning for many of these children was undesirable and unfeasible (McKenzie et al. 2020). Higher care needs militate against self-directed learning, especially in the absence of adapted tools such as assistive devices, and with the reality of unaffordable technology and social distancing. Routine disruptions negatively affect the mental health of children with developmental disabilities, including children with autism, and lack of supervision from working parents affects the health and safety of unsupervised children (Patel 2020; Holness & Aziz 2020; Aishworiya & Kang 2020). The mental health of parents of children with disabilities has been exacerbated during the pandemic due to higher stress levels, lack of social support, and higher caregiving burdens (Chen et al. 2020). These families require tailored support measures and assistance on how to better advocate for their children's rights, including in terms of access to education (Ashbury et al. 2020).

The Right to Access Health Care

Access to health care, including habilitation and rehabilitation and the provision of assistive devices to children with disabilities, is inconsistent and patchy (Grut et al. 2012; Saloojee et al. 2006). The legislation in the form of the National Health Act limits free health services to children under the age of 6 years (Buchner-Eveleigh 2016). Cross-sectoral coordination happens in theory, but not practice, including between government and DPOs and NGOs serving the disability community; consequently, disability needs are not prioritized in programs (Philpott 2006).

A study in Orange Farm, Gauteng, found that only 28% of the assistive devices needed by the children were received and that children with physical disabilities were more likely to obtain rehabilitation services than those with intellectual disabilities – at 44% compared to 8%, respectively (Saloojee et al. 2006). Provision of assistive devices depends not only on financial affordability, but also its fit with the child concerned, which may require home and school visits – interventions which rehabilitation professionals rarely implement (van Niekerk et al. 2019). Challenges with inappropriate assessments that determine the eligibility of children with disabilities and chronic illnesses to benefits such as social assistance can compound access to health services (Berry & Smit 2011).

The Esidimeni tragedy focused the world's attention on state negligence and the slow pace of deinstitutionalization that impinge on the rights of persons with psychosocial and intellectual disabilities in South Africa (Makgoba 2017; Moseneke 2018). That case dealt with the neglect and deaths of adults with psychosocial and intellectual disabilities. The SAHRC (2017b), after its investigation into mental health care provision in South Africa which was spurred by the tragedy, notes the lack of access to mental health care for children and adolescents, and specifically refers to a lack of bed capacity in psychiatric institutions where children are housed in adult wards or are placed in juvenile detention centers.

Gcaza and Lorenzo (2008) call for DPOs to support the advocacy and lobbying role of parents and caregivers seeking access to assistive devices and services.

The Right to Social Assistance

The disability grant for adults or the care dependency grant for children often acts as income for extended families (Goldblatt 2009; Wright 2015). As a result, the grants are not fully utilized for the child or adult with the disability. The amount of the grant, however, is also often cited by caregivers as being insufficient to meet the needs of children with complex or high support problems (Pretorius & Steadman 2018).

The launching of litigation in the case of *Hassan v Department of Social Development* (2012), cited in Legal Resources Centre 2012 ensured that regulations were amended to extend the provision of care dependency grants (grants for the care of persons with severe disabilities) to the children of refugees, after litigation was brought by a refugee parent (Legal Resources Centre 2012). The Department agreed to extend this grant to children of refugees. Piecemeal victories have been sought for social assistance for refugees in different categories (e.g., disability grants, social relief of distress grants) from litigation initiated in 2005 (Lawyers for Human Rights 2005). A single mother's activism on behalf of her child brought sweeping social justice change for refugee children.

Similarly, in *Ngalo v South African Social Security Agency* 2013*,* the launching of court proceedings forced the agency responsible for social grants to process an application for a care dependency grant that had been stuck in the system for 2 years. A punitive cost order was granted in favor of the mother of the 11-year-old child with septic arthritis and a hip deformity, despite the case being settled, as the mother "achieved substantial success" especially as the state agency "was moved, upon service of the application papers, to process and approve the grant" (para 28).

The Rights to Freedom from Violence and Access to Justice

The Optimus study (Ward et al. 2018) into the prevalence of sexual offenses against children in South Africa identified that children with disabilities are at a significantly higher risk of sexual abuse. Due to their vulnerability to crime and gender-based violence, children with disabilities interact with the justice system, where they encounter unaccommodating and inaccessible court proceedings (Hesselink-Louw et al. 2003; Dagut & Morgan 2003). Numerous barriers to participation in criminal courts are faced by persons with limited to no functional speech (LNFS), including children. These include perceptions of their (in)ability to testify in court due to their communication impairment (White et al. 2015; White et al. 2018; White et al. 2020). Not only do children and their parents and caregivers lack knowledge of the legal system, but stakeholders such as social workers, the police and magistrates or judges lack knowledge on how to help a person with LNFS during the process (Bornman et al. 2016).

Augmentative and Alternative Communication (AAC) for promoting access to justice for persons with complex communication disabilities, as a measure of accommodation, is used in some courts (Bornman 2017). The impact of the limited accessibility enhancing, procedural and reasonable accommodation measures in the Regulations relating to the Sexual Offences Courts (2020), has not yet been tested. A pilot study by Heath et al. (2018, p. 12) on the uptake of protective measures, such as court preparation in Sexual Offences Courts, highlighted the following distressing anecdotal information:

> People with disabilities: On average prosecutors and Regional Court magistrates estimated that children and adults with disabilities (with an emphasis on adults and children with mental and intellectual disabilities) comprised 10-15% of their cases, with a notable increase in such cases over the last 5 years. While specific statistics on complainants with intellectual disabilities are not available, most of the court actors had not received specific training on consulting with or preparing persons with intellectual disabilities. Senior stakeholders confirmed that many of these cases are not making it to trial and corroborate the statements of some prosecutors that these types of cases get screened carefully and withdrawn early.

Pasha (2012) notes the paucity of studies on sexual offenses perpetrated against adolescents with intellectual disabilities. Meer and Combrinck (2017) highlight families' gatekeeping – stopping particularly women and girls with intellectual disabilities from accessing justice due to fears of the futility of seeking recourse or the loss of income or experiencing stigma. Cape Mental Health et al.'s (2018) shadow report submission to the Committee on the Rights of Persons with Disabilities, identified barriers such as inaccessible police stations, environmentally and attitudinally, and other systemic problems such as a lack of appropriate training for testifying in court. Parents' perspectives in seeking justice – by activist means or others – for their children with disabilities who are victims or witnesses of sexual offenses, are not provided in the literature.

In *De Vos N.O. & Others v Minister of Justice & Constitutional Development & Others* 2015, the Constitutional Court found that it was not constitutionally permissible to constrain the discretion of presiding officers to require automatic detention in prison or psychiatric institutions of adults (and adolescents) with severe intellectual disabilities awaiting trial – where their competence to stand trial was not determined or where they were deemed "unfit" to stand trial. In the case, a young man, who was 14 years old at the time when he allegedly committed the offense, was represented by a curator ad litem. His mother was a co-applicant. Unfortunately, the court was not seized with determining the permissibility of depriving such persons of their legal capacity under the current substituted legal regime. Authors have, however, welcomed the amendment to the legislation that was brought to address the unconstitutional deprivation of their freedom and security of the person and of children's rights, that now provides for a variety of "less restrictive alternatives" to imprisonment (Khan 2017; Pienaar 2018).

The next section articulates the potential for parents to be either protector or violator of their children's rights.

Parents as Protectors, Advocates, and/or Violators

Parents' as activists on behalf of their children rely on their own political agency. In the workplace, for example, where employers do not support the family responsibility of their employees, parents of children with disabilities struggle to maintain work/home balance – particularly where children's specific needs are not accommodated. The example of parents of autistic children is discussed in this regard.

Similarly, the extent of stigma against parents of children with disabilities can also militate against their own actions as agents. Here the example of mothers of children with albinism is discussed. On the other hand, the growth of the "anti-vax" lobby illuminates the potential of parents to be the violators of their children's rights. Ethical conundrums arise in cases such as "wrongful life" suits.

Langan (2011) describes the controversies about causes and cures for autism and parental involvement in either camps, and shows that parental activism can be a powerful tool – for example against the anti-vaccination movement. A study of parental activism in relation to this issue has not been conducted in South Africa. However, a profile of online anti-vaccination lobbying in South Africa found that of the online content reviewed, 66.7% of the content on web pages were related to the thimerosal/mercury/autism and other diseases claim (Burnett, et al. 2015). Farham (2019) questions whether the anti-vaccination movement is rooted in "wilful ignorance or misunderstandings" and credits the retracted Wakefield study for anti-vaccination sentiments by parents of children with autism in the country. Studies on the impact of anti-vax parental activism on the rights of children with disabilities are needed in South Africa, particularly in the COVID-19 era.

Children with autism suffer greatly when their routine, access to therapies, schooling, and lack of respite care for their carers are disrupted. Parental anxiety and coping is severely affected by the isolation and heightened burden of care without access to supportive therapies (Amorim et al. 2020). A DPO in Durban, Action in Autism, noted increased requests for assistance and advice from parents of children with autism during the strict lockdown (level 5) in March 2020. Holness and Aziz (2020) explain how the DPO noted, in particular, parents' complaints that employers lacked an appreciation of their family responsibility at an unprecedented time where children were out of school, isolated, and subject to the care of working (and sometimes single) parents. In two separate instances reported by the authors, the parents' attempts to negotiate with their employers for flexible work arrangements to accommodate their child care responsibilities were initially unsuccessful.

One example cited by Holness and Aziz is that of two autistic brothers, aged 12 and 7 years, who were left in the care of their adult sister with an intellectual disability, while their single mother, a nurse, worked as an essential worker. The older boy had high support needs. The meltdowns that ensued when the boys were inadequately supervised escalated to dangerous behavior where one son climbed to the roof of their building, requiring a rescue from the fire department. Numerous neighbor concerns about the safety of the children were noted. Despite the letter of support from the DPO, the mother's application to her employer for paid leave to allow her to care for her children and grandchild – all with disabilities and requiring high-level support – was denied.

Another complaint emanated from a parent where a nuisance complaint was brought in a sectional title scheme apartment block, against his child, a 19 year old autistic adult. Threats were made to have the young person removed by the SAPS or social welfare due to the noise he made while stimming. The state's regulations banned exercise for a period during the lockdown, with the result that the behavior deteriorated. The DPO's intervention, through correspondence, prevented his arrest. However, the body corporate continues to threaten to have the young man institutionalized. A plea by disabled persons organizations to the President for a relaxation of COVID-19 government exercise restrictions to benefit autistic persons was unsuccessful (Broughton 2020).

These DPO advocacy attempts are still required because of the lack of a precedent in establishing the right to family responsibility of parents of children with disabilities in the workplace. A Labour Court settlement was reached in a case where the mother of a child with autism was unfairly discriminated against when she required reasonable accommodation of her family responsibility (*Hugo v eThekwini Municipality*, Durban High Court, Case Number D18/11 cited in Holness 2016a) after repeated unilateral, unreasonable, and unlawful transfers. In the *Hugo* case, the single mother of a young child with autism sought reasonable accommodation of her family responsibilities in respect of the care of her son through appropriate shift work and being based at a police station close to his school. These adaptations to her work life were needed after she experienced immense challenges with her son's care and behavior as a result of her inconsistent routine and working far from home and school – resulting in multiple changes and transfers at work. The eThekwini Municipality's metropolitan police, her employer, refused to accommodate her. She claimed unfair discrimination on the basis of gender and family responsibility in terms of section 6(1) of the Employment Equity Act 55 of 1998.

A settlement agreement made an order of court after the testimony of the expert witness, a psychologist, was led on the affect of the mother's unsociable working hours on the care of the boy, including leading to self-harming behavior and regressing in terms of developmental milestones. The mother brought the case with the assistance of a law clinic, the Legal Resources Centre (the LRC). Unfortunately, individualistic outcomes, particularly where settlements are reached and precedents are not established as a result, mean that discriminatory conduct of employers needs to be litigated where employees cannot successfully negotiate workplace adjustments to accommodate their family responsibilities (Holness 2016a). The complaints made by parents of children and young adults with autism to Action in Autism regarding care responsibilities of parents of children with autism during the COVID-19 era are an example of this continuing challenge.

Children with albinism are possibly the most marginalized and vulnerable to harm in Sub-Saharan Africa, including South Africa, where they are murdered for muti (witchcraft) (Taylor et al. 2019; Mswela 2017). Mothers with albinism and those whose children have albinism (collectively known as mothers impacted by albinism) face dire consequences of discrimination that include ostracism and potential death (Reimer-Kirkham et al. 2020). Legal approaches to protect persons with albinism have sometimes jarred with the question of identity (Possi & Possi 2017). Nonetheless, a disability approach is useful, as albinism, if construed a disability in the legal sense, can extend protections and accommodations for persons with albinism. The challenge is the continued stigma that mothers and children face – even in schools and health facilities. The Centre for Human Rights of the

University of Pretoria included mothers affected by albinism in a multi-state project to find sustainable solutions for the challenges they face (Centre for Human Rights 2020). The myths facing persons with albinism can be deconstructed to provide culturally neutral explanations (Baker et al. 2010). The effectiveness of activism by mothers of children with albinism for their children needs further study.

The ethical and moral quagmire posed by "wrongful life" suits is not limited to South Africa (Human & Mills 2010). In *H v Fetal Assessment Centre*, 2015, the Constitutional Court provided some guidance to lower courts on what considerations should be taken into account when deciding whether to develop the common law in favor of recognizing these kinds of suits. Historically, South African law has not recognized these suits (Mahery 2016) but has recognized wrongful birth suits (Boezaart 2015). In the *H* case, a claim for damages was sought by the mother on behalf of her six-year-old son due to alleged wrongful and negligent failure of the assessment provider to advise the mother of the risk of her child being born with Down Syndrome. The boy also had other severe health challenges. The High Court refused the matter, citing previous court decisions. It stated that public convictions had not changed in the interim, as instead "public opinion continues to be influenced by the remarkable resilience in overcoming enormous odds displayed by many disabled persons in all walks of life, refuting those who 'treat their lives as inferior to non-existence'" (para 29). The Constitutional Court's decision aimed to remove the emotive elements from the legal debate on recognizing the wrongfulness inherent in these instances and left it to the lower court to decide on the viability of this child's claim (as represented by his mother). This is particularly as the Court posited that a child's claim may in principle exist. Some authors support the bringing of "wrongful suffering" claims such as in the *H* case, in line with the principle of the best interests of the child (Britz & Slabbert 2015; Neethling 2016). This case was brought by a mother in her representative capacity as the parent of the child. Boezaart (2015) posits that the appointment of a curator ad litem for this child may have been apt to represent the child's interests. The notice of motion brought in the Constitutional Court is anonymized to protect the child's identity. However, the entire description of the mother's stance on behalf of her child is redacted from the pleading, making it difficult to unpack her representations on behalf of her child.

Discussion

While the literature on parent-led activism in South Africa is sparse, the richness brought by parents' perspectives of conditions and partnerships that are conducive to successful activism in studies such as Elphick et al. suggests the need for further academic study. While the "burden" of child care is articulated in the literature, parents' activism in obtaining access to services for their children is not generally studied. The use of peer-support groups is a positive, semi-formal method of gaining communal input into areas requiring activism and is well positioned to lobby collectively. However, three studies identified the need for DPOs and NGOs to capacitate and support parents and parent groups in advocating for their children (Philpott 2006; Elphick et al. 2014; Philpott & Muthukrishna 2019). The possibility of amplifying their voices through strategic partnerships with DPOs and NGOs that capacitate and support them without imposing their own objectives should be further studied. Elphick et al. (2014) detailed the traditional tools for activism used by parents and caregivers – advocacy, lobbying, and protesting. Some of the litigation discussed was preceded by these methods, such as the *Springate* and *Western Cape Forum for Intellectual Disabilities* cases. The DPOs/NGOs involved conducted various campaigns to advance their causes prior to and following the litigation. DeafSA continues to lobby for change in sign language provision in schools and the WCFID continues to seek accountability from government in complying with the court order.

The roles of parents and caregivers in utilizing litigation as a strategy differ depending on the forum utilized; the litigation strategy of the legal representatives; and the objectives. For example, the parents' roles in the Equality Court cases were to identify the rights violations their children suffered to the courts, but these cases were not "strategic impact" cases. In other words, the remedies obtained for their individual children did not create a precedent or systemic changes. On the other hand, an Equality Court case brought by an attorney who is a wheelchair user, brought widescale changes to the accessibility of court infrastructure in South Africa (*Muller v Department of Justice & Another* 2003, discussed in Holness & Rule 2014). In other forums, such as the High Court cases, precedents were set in a number of cases, such as the *Centre for Child Law* and *Western Cape Forum for Intellectual Disability*, cases – with varying levels of compliance by the state in implementing the court orders. Immediate compliance in *Centre for Child Law* seems to have been possible because of the nature of the relief sought – for a number of children at one institution. However, the systemic changes required for a group of 1500 children in one province from multiple educational institutions is still problematic. In five cases listed in the table below, law clinics represented the litigants – three of which were the mothers of the children and two were NGOs. Three litigants who were the mothers of the children they represented were legally represented by private law firms, one of which was pro bono. Only in one instance did Legal Aid South Africa, the civil and criminal legal aid provider of the state, represent a child. This representation was by a curator ad litem. Curators ad litem were only appointed in two cases: one for children with behavior conduct disorder and the other for a person with a severe intellectual disability. Four of the cases resulted in settlement agreements (or orders by consent of the parties), and one was withdrawn. DPOs were amici in two cases, while in one a DPO was a co-applicant. Skelton interrogates the role of the amicus curiae in children's litigation, praising their substantial contribution to the jurisprudence (Skelton 2017). There is more scope for DPOs to assist the courts as amici in the future. In three cases with DPO involvement, not as the main litigants, two cases were settled. This means that DPO involvement does not necessarily mean that a court order setting a precedent is likely to result. Only three of the cases listed below are still not satisfactorily resolved. The role of mothers of children with disabilities in litigation on the rights of children with disabilities can therefore not be denied.

There is no ombudsperson for persons with disabilities. The SAHRC as the national human rights institution (NHRI) responsible for the protection of the rights of persons with disabilities in South Africa, intervened (as legal representative) in only one of the cases. It did so after litigation commenced and when a complaint was laid to its offices. There is therefore much scope for dedicated interventions by the SAHRC to help children with disabilities and their parents and caregivers to agitate for change.

Table Reported and unreported cases regarding children with disabilities

Court case	Litigants	NGO or DPO involvement	Legal representation of the applicant(s)	Outcome
Centre for Child Law Psychosocial support in alternative care	Law clinic		Curator ad litem appointed on behalf of the children	Court order: compliance
De Vos NO Automatic detention in prison or hospital	Child represented by curator ad litem.	Down Syndrome South Africa and Cape Mental Health (CMH) (High Court); CMH (Constitutional Court) as amici.	Curator ad litem and mother (second applicant) represented by Legal Aid South Africa	Court order: legislative amendment ensued
Equal Education (2017) Scholar transport	NGO	Siphisila Isizwe as amicus	Law clinic: Equal Education Law Centre	Settled: policy development not satisfactory
H Wrongful life suit	Child and mother of child		Private law firm	Court order: refer back to High Court for decision. Matter not yet resolved
Haskins Access to a private shop	Mother of child		Private law firm: pro bono basis	Court order: still no compliance
Hassan Social grants for refugee children	Mother of child		Law clinic: Legal Resources Centre (LRC)	Withdrawn: regulations passed
Hugo Reasonable accommodation of mother’s family responsibility	Mother of child		Law clinic: LRC	Settled: order implemented

(continued)

Ngalo Care dependency grant processing	Mother of child		Private law firm	Settled: grant application processed
Oortman Reasonable accommodation in a private school	Mother of child		South African Human rRights Commission	Court order: affecting the child concerned. Not strategic
Springate Sign language	Child and mother	DeafSA and special schools as co-applicants	Law clinic: LRC	Partly withdrawn/ settled: long-term objective reached
Western Cape Forum for Intellectual Disability case Education of children with severe and profound intellectual disabilities	NGO		Law clinic: LRC	Court order: declaration; structural interdict Long-term compliance problematic

Conclusion

Parents and carers have to navigate the complex system of legislation and policies and the limited remedies offered in uncoordinated systems and processes. Du Plessis (2013, p. 221) warns against policies that are ostensibly modeled on the promise of the social model of disability, yet “entrenches stereotypes, uncritically endorses the classification of disabled persons’ bodies and measures them against an ‘ideal’, and fails to engage with how policies for inclusion may end up creating new sites for exclusion.” Du Plessis (2013, p. 221) also questions the value of the rights-based models where much depends on whether these rights are

> interpreted to entrench the status quo or as discursive tools with which to fight domination and stake social claims. If the latter, it is not just the courts’ interpretations of their content that are important, but whether they are utilised by affected persons to appeal to political communities to include and value such persons.

On a micro-scale, parents will continue to agitate for their children’s access to services, despite the systemic failures and ableism permeating institutions. A responsive civil service and better coordination between service providers would cut down on opportunity costs, as well as the real costs incurred in seeking recourse for their children. Holding service providers accountable, through utilizing complaint mechanisms where failures occur and seeking strategic outcomes in the public interest, will continue to be necessary. Parents, caregivers, and children should utilize the existing child-friendly complaint mechanisms (such as the SAHRC's mechanism) and the Equality Courts, and test these for their accessibility. Access to information about children's rights is vital for empowering parents and caregivers. Such information should also be provided in accessible formats, such as Easy Read.

Professionals and organizations acting as curators ad litem and *amicus curia*, respectively, will likely continue to play an enhanced role in South African litigation on children's rights. The examples of parental activism and litigation such as the *Springate* case showed that where parents and caregivers of children with disabilities are backed up by DPOs with traction in society, they are more likely to be successful in achieving their advocacy goals. Furthermore, the role of law clinics well versed in disability in representing these children, their parents, and DPOs is crucial.

Perhaps a critique may be brought that the children's and parents' voices were drowned out by the DPOs/NGOs representing their "interests" along disability identity lines. Another construction may be that the DPOs/NGOs amplified the voices of the parents representing the children. The formalized way in which the voices of parents and caregivers were subsumed by the DPOs/NGOs in some cases does not necessarily affect their agency. However, it may overshadow their daily struggles at micro sites of activism where they and their children experience a continued lack of resources and suffer gross inequalities.

Skelton (2017) identified a few instances where children were directly involved in advocacy and litigation. Those did not include children with disabilities. Sloth-Nielsen (2019) argues that the courts recognize children's evolving maturity. However, in some cases an awareness of their autonomy is clear, yet in others a more protectionist stance is evident. What is evident from the litigation discussed in this chapter is that children's voices were only heard in one case (the *Springate* case). The Constitutional Court has called for children's voices to be heard in litigation about them (*MEC for Education: KwaZulu-Natal and Others v Pillay*, 2008) and was critical of only the mother of the child being heard. Obtaining the voices of children with disabilities in the activism for their rights is imperative. This will require dedicated measures to facilitate their full participation, including accessibility and reasonable accommodation requirements – particularly where communication disabilities are concerned.

Reimer-Kirkham et al. (2019) criticize the lack of "endogenous advocates" in albinism scholarship. In the same way, much richness and authenticity can be brought to scholarship on parent-led activism where parents of children with disabilities speak to their experiences. For example, Crow and Merchant's (2019) reflection on not only being parents of children with disabilities but also as being parents with disabilities. Parents and caregivers will likely remain at the forefront of activism until children with disabilities are granted the tools and supportive forums to raise their own voices to help formulate solutions for the barriers they face or are effectively represented by their parents and caregivers.

Lower prioritization of access to the basket of services to which children with disabilities are entitled is likely to be exacerbated after the COVID-19 pandemic, when states struggle to recover from its economic impact on healthcare systems. DPOs are already noting the lower priority that disability services have received in the last year (McKinney et al. 2020). Future research will have to garner empirical data on the impact of COVID-19 measures on children with disabilities in South Africa, similar to data garnered elsewhere in Africa, such as in Uganda (Mbazzi et al. 2021; Latzer et al. 2021). Aishworiya and Kang (2020) identify that the traditional advocacy role of parents is likely to be more challenging during the pandemic. They call for education, health, early intervention, and social services to prioritize children with disabilities, in order to avoid long-term prejudice occasioned from lack of key social, educational, and health interventions during this period. Importantly, the effectiveness of strategies that parents and caregivers rely on to successfully advocate for their children's rights should be studied from a Global South perspective. There needs to be a renewed focus by scholars to source the voices of parents of children with disabilities, in order to understand their role in agitating for change.

There seems to be consensus that accountability for service provision to persons with disabilities, particularly children with disabilities, may come from comprehensive disability-specific legislation. This is because the current fragmented legal and policy formulations make it difficult for parents to navigate the bureaucratic obstacles to obtaining services for their children (Tigere & Makhubele 2019; Kamga 2016a). The SALRC should prioritize a legislative framework for accountability in ensuring the provision of health, social security, education, and other services to children, in its investigation into the domestication of the CRPD in South African law. The continued stigma that parents and their children with disabilities face in communities undermines their efforts to advocate for their children (Mkabile & Swartz 2020b). Stigma-reduction measures should be prioritized, whether in policy or legislation, and should be properly funded to drive the ableism inherent in stereotypical perceptions of disability at a community level, as well as in relevant sectors of society – including public service.

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Genesis and the Current State of the Global Maxim “Nothing About Us Without Us”

79

María Soledad Cisternas Reyes and María Graciela Iglesias

Contents

Abstract

This chapter documents the concrete implementation of the principle “Nothing About Us Without Us” through the Disability Rights Movement, especially during the elaboration of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The implementation of this principle by disability rights groups has led to unprecedented changes in social, legal, and political systems, which has brought about a paradigm shift from the medical model of disability to the social and human rights models. Years later, the principle was even reflected in the Sustainable Development Goals of the 2030 Agenda. The chapter also shows that there is still progress to be made with regard to how

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psychosocial and intellectual disabilities are situated within disability rights work, so that “Nothing About Us Without Us” can become a full reality.

Keywords

United Nations Convention on the Rights of Persons with Disabilities · 2030 Agenda for sustainable development · Psychosocial disability and intellectual disability

Introduction: “Nothing About Us Without Us” in the Elaboration of the United Nations Conventions on the Rights of Persons with Disabilities, CRPD

In 1983, the United Nations proclaimed the Decade for Disabled Persons culminating in the approval of the Standard Rules for Equal Opportunities for Persons with Disabilities, a Resolution approved by the United Nations General Assembly.[1] In this document, we begin to see how some elements of the social model of disability are adopted by the Resolution, and the ways in which the text recognizes the decisive role persons with disabilities and their representative organizations should play in the planning and execution of all measures that affect their civil, political, economic, social, and cultural rights.

During the 2001 World Conference against Racism, Racial Discrimination, Xenophobia, and Related Forms of Intolerance in Durban, South Africa, the delegation of Mexico proposed the development of a comprehensive International Convention for the promotion and protection of the rights of persons with disabilities, which was materialized in Resolution 56/168 that formed the Ad hoc Committee of the United Nations for this work. The proposal was advanced by Gilberto Rincón Gallardo, President of the National Council to Prevent Discrimination (CONAPRED). Gilberto was not only representing his government as an official but as a person with disability himself.

The sessions of the Committee began in 2002, and persons with psychosocial and intellectual disabilities, their representative organizations, and experts with disabilities from various delegations had a strong presence from the start. They provided a significant contribution in the preparation of the text of the Treaty on Human Rights, directly and intensively advocating with the official delegations of the United Nations member states to commit to the different issues of “disability.” The negotiations comprised eight sessions, ending in 2006, and throughout these sessions, the principle of “Nothing About Us Without Us” guided the work. Indeed, all those involved in the process understood the importance of persons with psychosocial and intellectual disabilities participating in the convention, demonstrating how the principle was operationalized in the UN setting.

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[1] Normas Uniformes para la Igualdad de Oportunidades de las Personas con Discapacidad. Resolución 48/96, del 20 de diciembre de 1993.

The Convention conceptualizes disability through the social/human rights model, which defines disability as the result of the interaction between persons living with impairments and an environment filled with physical, attitudinal, communication, and social barriers. The Convention therefore implies that the environment must change to enable persons living with impairments to participate in society on an equal basis with others. Unlike the charity or medical model – in which persons with disabilities are "objects" of charity, medical treatment, and social protection – the social/human rights model views persons with disabilities as "subjects" with rights, who are capable of claiming those rights, able to make decisions for their own lives based on their free and informed consent and be active members of society.

The Treaty establishes three substantive pillars, developed as a result of the participation of persons with disabilities who embraced the principle "Nothing About Us Without Us."

The first pillar, accessibility, is a legal term that had not been specified or developed in other human rights treaties. The CRPD refers to accessibility from the preamble[2] and in the general principles.[3] Specifically, the CRPD prescribes that the States Parties adopt pertinent measures to ensure access for persons with disabilities, on equal terms with others, to the physical environment, transportation, information and services, communications, including information and communication technologies and systems, and other services and facilities open to the public or for public use, both in urban and rural areas, so that persons with disabilities can live independently and participate fully in all aspects of life.[4]

The Convention has considered this legal innovation so relevant that it defined universal design, on which accessibility should be based, as "the design of products, environments, programs and services that can be used by all persons, to the greatest extent possible, without the need for adaptation or specialized design." Of note, however, universal design does not exclude technical aids for particular groups of persons with disabilities, when needed.[5] Organizations of persons with physical disabilities and sensory disabilities made a strong impact on bringing about this legal innovation. Furthermore, the Convention emphasized the importance of providing information and communications in accessible formats and also the use of sign language for Deaf persons.[6] These norms require not only the recognition of accessibility in the internal legislation of countries but also the development of plans for the allocation of a specific budget for this purpose.

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[2] CDPD, Preámbulo, letra v): Reconociendo la importancia de la accesibilidad al entorno físico, social, económico y cultural, a la salud y la educación ya la información y las comunicaciones, para que las personas con discapacidad puedan gozar plenamente de todos los derechos humanos y las libertades fundamentales.

[3] Ibid, art. 3, letra f).

[4] CDPD, op. cit. art 9.

[5] Ibid, op.cit. Art 2.

[6] Ibid, op. cit. Art.21.

The second pillar focuses on respect for inherent dignity and individual autonomy, including the freedom to make one's own decisions, which first appears in the preamble[7] and as the first general principle of the Convention.[8] This pillar is the heart of the treaty and operationalizes the principles of respect and autonomy through the definition of "legal capacity." It prescribes that "States Parties shall recognize that persons with disabilities have legal capacity on an equal basis with others in all aspects of life" and that they shall adopt the pertinent measures to provide access to persons with disabilities to the support that they may need in order to exercise their legal capacity, with adequate and effective safeguards to prevent abuses in accordance with international human rights law. This norm changes the traditional approach of the civil codes of the nineteenth century based on the supposed "protection" of persons with disabilities towards the vision of a rights holder that exercises their autonomy and decisional freedom.

In other words, this precept requires the legal and philosophical reinterpretation of the pro-personae principle, forcing awareness and impacting areas of law such as civil law, criminal law, and procedural law, among others. In cases when the legal capacity of a person is not respected, especially in safeguarding their physical or mental integrity, such as involuntary sterilization, invasive, or irreversible surgeries without free and informed consent, or forced hospitalizations, those can now be classified as "torture and other cruel, inhuman or degrading treatment or punishment."

We are in the presence of a transcendental achievement with the rise of organizations of persons with psychosocial and disabilities, as well as organizations of Deaf persons and deafblind persons whose populations have been affected by disability labels and the appointment of guardians. In a metaphorical sense, the Convention's adoption of the "Nothing About Us Without Us" principle marks the abolition of another form of slavery, opening the door for many persons with disabilities to have their own voice and the full exercise of their legal capacity.

The third pillar is the right to live independently and to be included in the community, which appears in the preamble[9] and in the general principles of the

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[7] Ibid, op. cit. Preámbulo, letras m): Reconociendo el valor de las contribuciones que realizan y pueden realizar las personas con discapacidad al bienestar general ya la diversidad de sus comunidades, y que la promoción del pleno goce de los derechos humanos y las libertades fundamentales por las personas con discapacidad y de su plena participación tendrán como resultado un mayor sentido de pertenencia de estas personas y avances significativos en el desarrollo económico, social y humano de la sociedad y en la erradicación de la pobreza; y letra n): Reconociendo la importancia que para las personas con discapacidad reviste su autonomía e independencia individual, incluida la libertad de tomar sus propias decisiones.

[8] Ibid, op. cit. Art. 3, letra a).

[9] Ibid. Op. cit. Letra m): Reconociendo el valor de las contribuciones que realizan y pueden realizar las personas con discapacidad al bienestar general ya la diversidad de sus comunidades, y que la promoción del pleno goce de los derechos humanos y las libertades fundamentales por las personas con discapacidad y de su plena participación tendrán como resultado un mayor sentido de pertenencia de estas personas y avances significativos en el desarrollo económico, social y humano de la sociedad y en la erradicación de la pobreza.

Convention, in terms of "... the independence of persons"[10] and their social inclusion. This pillar asserts that persons with disabilities should have the opportunity to choose their place of residence and where and with whom to live, on an equal basis with others, and not be forced to live according to a specific way of life. The Convention proposed that in order to ensure persons with disabilities are able to fully exercise their rights; the systems of institutionalization must be eradicated. Moreover, the Convention asserts that persons with disabilities should have access to a variety of home care, residential, and other community support services for the general population, avoiding their isolation or separation from it.

This is an immense achievement, spearheaded by organizations of persons with psychosocial disabilities and intellectual disabilities, who powerfully and effectively asserted "Nothing About Us Without Us."

The Committee also relied on the principle of "Nothing About Us Without Us" when it developed accountability measures. The Committee established that civil society, and in particular persons with disabilities and the organizations that represent them, must be integrated and fully participate at all levels of the Convention's implementation process.[11] When establishing the international monitoring mechanism through a Committee, various eligibility criteria are indicated for its members, such as a balanced gender representation and the participation of experts with disabilities.[12]

Sustainable Development

The Millennium Development Goals (year 2000) did not include persons with psychosocial and intellectual disabilities in their goals and indicators. "Nothing About Us Without Us" was the guiding principle persons with disabilities advocated for during the development of the 2030 Agenda and its Sustainable Development Goals.

While the Millennium Development Goals (year 2000) did not include persons with psychosocial and intellectual disabilities in their goals and indicators, activists determined to change this for the 2030 Agenda adopted the guiding principle of "Nothing About Us Without Us" during the development of the 2030 Agenda and Sustainable Development Goals.

At the High Level Meeting on Disability and Development (HLMDD, 2013), the Official Declaration of the United Nations Committee on the Rights of Persons with Disabilities emphasized the human rights approach and the importance of equality

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[10] Ibid, op.cit. art. 3, letra a).

[11] Ibid, op.cit. art. 33, N° 3.

[12] Ibid, op. cit, art. 34, N° 4.

and non-discrimination for persons with disabilities, guaranteeing their right to inclusive, accessible, and sustainable development.

As a result of the intense work, the 2030 Agenda and its Sustainable Development Goals expressly mention persons with disabilities: SDG No. 4 Guarantee an inclusive quality education and lifelong learning; SDG No. 8 Promote economic growth, employment, and decent work; SDG No. 10 Reduce inequality within and between countries; SDG No. 11 Make cities and human settlements inclusive, safe, resilient, and sustainable; and SDG No. 17 Strengthen the means of implementation and revitalize the global partnership for sustainable development.

At the 8th Conference of States Parties to the CRPD / UN-NY: "Incorporation of the rights of persons with disabilities in the post-2015 development agenda," the Committee underlined the relevance of the Development Goals with indicators that directly consider persons with disabilities, in the five aforementioned Goals, while also highlighting the adoption of specific indicators on disability in two more Goals – End poverty in all its forms everywhere and promote peaceful and inclusive societies, provide access to justice for all, and build effective, accountable, and inclusive institutions at all levels – which did not expressly mention persons with psychosocial and intellectual disabilities.

Sustainable Development goals and indicators that expressly mention persons with disabilities are notable achievements for the movement of persons with disabilities at a global level and of the systematic work carried out by the United Nations Committee on the Rights of Persons with Disabilities.

Another achievement was the visibility of the disability issue in the High Political Level Forum (HLPF, 2018), where the opening message pointed out that a challenge for Sustainable Development is the reorientation of substantive approaches towards marginalized sectors of the population. It was proposed that sustainable development should consider universal accessibility. It was also underlined that multidimensional poverty is aggravated when there are groups of persons who cannot express their will, see their legal capacity restricted, or are denied the right to vote. This is a situation that affects millions of persons worldwide, including especially persons with psychosocial and intellectual disabilities.

The HLPF 2020s decision to set universal accessibility as a condition for the sustainable development of millions shows that disability has been mainstreamed within the United Nations. The Human Rights Council decided to incorporate a Special Rapporteur on the Rights of Persons with Disabilities in its body of Rapporteurs, held from 2014 to 2020 by a woman with a disability (Catalina Devandas Aguilar, 2014–2020). For his part, the Secretary General of the United Nations decided to appoint a Special Envoy on Disability and Accessibility in 2013, being succeeded by a woman as Special Envoy in 2017, in both cases, persons with disabilities (Lenín Voltaire Moreno Garcés, 2013).

The Secretary General even established a Unit on Disability in which a specialist with disabilities participates, in accordance with the policy of the United Nations Strategy for the Inclusion of Disabilities (UNDIS, 2019), which considers both the labor inclusion of persons with disabilities at the United Nations and universal accessibility.

United Nations Committee on the Rights of Persons with Disabilities

The first election of experts for the human rights treaty occurred in 2008 and adopted the eligibility criteria recommended in the Convention, prioritizing the presence of experts with disabilities. Indeed, 83% of the international experts elected by the States Parties (10/12) had disabilities.

The inclusion of expert candidates with disabilities reaffirmed the provisions of the Convention, particularly with regard to internal monitoring mechanisms which require the participation of persons with disabilities. Once again, "Nothing About Us Without Us" had concrete visibility, which has been maintained to date. In the recent election of the Committee (year 2020), 77% of the experts elected by the Committee (14/18) were persons with disabilities.

Efforts to ensure adequate representation of marginalized groups also resulted in significant gender diversity. In the first election, five female experts were elected, equivalent to 41% of the total Committee. In 2010, female participation consisted of seven experts, equivalent to 38% of the total number of members. In the last election (2020), the Committee was made up of 11 experts (61% of the total) (Table 1).

Since its installation, the Committee emphasized the participation of persons with psychosocial and intellectual disabilities and their representative organizations in different phases of the monitoring process through its Rules of Procedure, Guidelines for Reporting, and Working Methods. In the Rules of Procedure, regarding the admissibility criteria of an individual or collective communication in accordance with the Optional Protocol to the Convention, it is worth highlighting the rule that states "To decide whether a communication is admissible, the Committee will apply the established criteria in Article 12 of the Convention to recognize the legal capacity of the author or victim before the Committee, regardless of whether or not the State party against whom the communication is directed." Undoubtedly, this regulation is a strong expression of "Nothing About Us Without Us" consigned by the monitoring mechanism.

The Committee was in charge of preparing guidelines for the participation of organizations of persons with disabilities and civil society organizations in the

Table 1 Elections every 2 years to integrate the CRPD Committee

Conference of States Parties to the Convention on the Rights of Persons with Disabilities	Total of chosen experts	Experts with disabilities	Women with disabilities
1st session. October 31 to November 3, 2008	12	10	5
3rd session. September 1–3, 2010	18	16	7
5th session. September 12–14, 2012	18	16	7
7th session. June 10–12, 2014	18	16	6
9th session. June 14–16, 2016	18	14	1
11th session. June 12–14, 2018	18	12	5
13th session. November 30, December 1 and 3, 2020	18	14	Pending information

reporting processes by the States, thereby reiterating the importance of the participation of those directly involved.

The impact of "Nothing About Us Without Us" also led to the beginning of mainstreaming the issue in other Committees, for example, in the Committee on the Rights of the Child. It has similarly led to the mainstreaming of experts with disabilities in other Committees, such as in the Committee for the Elimination of Discrimination against Women CEDAW, with the election of an expert with disabilities in the year 2018, for example.

Undoubtedly, civil society organizations of persons with disabilities at a global level, both individually and grouped together in the International Disabilities Alliance (IDA), have demonstrated the principle of "Nothing About Us Without Us," both in the United Nations and internationally. These organizations include the African Disability Forum, Arab Organization of Persons with Disabilities; ASEAN Disability Forum; Down Syndrome International; European Disability Forum; Inclusion International; International Federation of Hard of Hearing Persons; International Federation for Spina Bifida and Hydrocephalus; Pacific Disability Forum; RIADIS World Blind Union; World Federation of the Deaf; World Federation of Deafblind; and World Network of Users and Survivors of Psychiatry.

Other Readings of "Nothing About Us Without Us"

"Nothing About Us Without Us" imagines persons with psychosocial and intellectual disabilities participating in different aspects of society including the design, preparation, implementation, and monitoring of public policies and legislation.

The genesis of the slogan was and has been to highlight the irreplaceable role of persons with disabilities, which is in line with the Convention. In other words, no one could claim the "representation" of persons with disabilities.

However, there are two aspects that we must take into account:

Regarding the expression "we," the relatives of persons with disabilities also want to be incorporated so that their opinions and contributions are considered, as a complement to the actions of persons with disabilities.

A second aspect refers to the fact that persons with disabilities should not only participate in matters related to disability but also in any other matter in the community.

Persons with psychosocial and intellectual disabilities are crossing the social fabric, without distinction and, therefore, as inhabitants of a territory and as citizens regardless of their age or condition, they have the right to broad political and public participation. This has led to the reformulation of the expression: "everything with persons with disabilities."

"Nothing About Us Without Us": Psychosocial and Intellectual Disability

Persons with psychosocial disabilities experienced the historical reality of devastation as a result of the treatment of their condition. Understanding the person as an ineffable and ungraspable being, they have been objectified and trapped in diagnoses that were only treated through institutionalization and/or exclusion from community life, based on the belief of their dangerousness and the need to control their behavior. The disability/illness formula found them subject to public policies that built asylum models in the countries, an example of this is the construction of the panopticon as a paradigm of care, as established through the disciplinary control of the body, constituting a "state of exception."

The state of exception is the device that must, ultimately, articulate and keep together the two aspects of the legal-political machine, instituting a threshold of undecidability between anomie and nomos, between life and law, between auctoritas and potestas. This is founded on the essential fiction by which anomie – in the form of the auctoritas, the living law or the force-of-law – is still in relation to the legal order and the power to suspend the norm is prey.

Systems become entrenched when international law is ignored while internal mechanisms seek to produce a permanent state of exclusion, which nevertheless pretends to be applying the law.

The harmony and interdependence of the rights that the CRPD brings in exercise and accessibility will settle the systems that still remain without recognizing the active citizenship of persons with psychosocial disabilities.

Human Rights and the Path to the CRPD

From 1960 onwards, Human Rights are raised as a rule of proportionality, as a right, as an action, as a principle, as a value, and as an exception. The impact that recognized rights produce establishes an epistemological change where concepts are de-centered and established in a continuous movement, through intersubjective dialogue, "Democratic plurality is the recognition of diversity and difference; above all, to the pragmatic use that citizens make of social discourses when they want to be part of the democratic dialogue." It is the thesis that Habermas maintains, when he considers that communicative pragmatics is the reference to which political practice must be associated if it is to delve into the symbolic components and the representations made by citizens of the State and its institutional organization systems. Democracy should be communication without exclusion; it is the political program that will allow each citizen to direct their actions in correspondence with a social participation where agreement and consensus allow them to recognize the interests and common goods that should guide society. It is in the field of intersubjectivity that the recognition of the other makes justice, equity, and human solidarity possible.

Equality in the CRPD is proclaimed as a fundamental condition; while "The rights of freedom behave equally with the principle of equal treatment. Regarding the rights of freedom, the principle that all men are equal serves. In Locke's state of nature, which has been the great inspiration for the declarations of human rights, men are all equal, where by 'equality' it is understood that they are equal in the enjoyment of freedom, in the sense that no individual can have more freedom than another."

The Convention views access to information as a key condition of achieving equality, as this access grants persons the ability to communicate, to make decisions, and to otherwise exercise their civil rights through the elimination of the barrier between individuals with and without disabilities. In the Convention on the Rights of Persons with Disabilities (arts. 14, 22 et seq) the right to equality is viewed as a principle, as a value, and as an action.

Reference is usually made to the dignity of persons with psychosocial and intellectual disabilities, without taking into account that recognition of the dignity of persons implies that they move in the three spheres of dignity, this is the recognition of their ability to reason, to choose, and communicate. These features are gradual, relative and abstract, and imply leaving behind the valuation of the human being because of its usefulness, in the sense that Bobbio assigns it when he points out "Less socially useful less valuation as a human being." This concept implies the operability that Article 12 of the Convention on the Rights of Persons with Disabilities brings, entitled "equal recognition as a person before the law." The harmonization of Article 12 with the capacity to act entails the recognition that persons with psychosocial and intellectual disabilities are on the same footing as others; being able to make their decisions with the support that is required for them demonstrates the concept of dignity that we have referred to.

In short, being on the same footing is to be able to have life goals, to have the means to carry out those goals, and to not to be discriminated against on the basis of disability. Persons with psychosocial and intellectual disabilities may require a diversity of supports that in each case, as in the life of any person, are linked to their history and narrative, loneliness, absences, powerlessness, and success. The social construction of disability demonstrates the relationship between the environment and the person. The lack of understanding, failures in communication, and the continued othering of persons with intellectual and psychosocial disabilities are barriers to the full community inclusion of persons with disabilities. However, the global movement is seeking to influence the organization and empowerment of the rights of persons with psychosocial and intellectual disabilities. Without centering these groups and valuing their preferences above other factors, an effective inclusion model cannot be argued.

The current status of accessibility and public policy in most countries continues to stand as a major barrier to Article Eight of the Convention, equal recognition as a person before the law.

Participation: Nothing About Us Without Us

In this sense, one of the main tensions to overcome is linked to the defense of sectoral interests and the continued development of policies without the inclusion of persons with psychosocial and intellectual disabilities or disability organizations.

La Observación General N° 7 (2018), sobre la participación de las personas con discapacidad, incluidos los niños y las niñas con discapacidad, a través de las organizaciones que las representan, en la aplicación y el seguimiento de la Convención, elaborada por el Comité sobre los Derechos de las Personas con Discapacidad de Naciones Unidas, ha señalado que "El derecho a participar es un derecho civil y político y una obligación de cumplimiento inmediato, sin sujeción a ninguna forma de restricción presupuestaria, aplicable a los procesos de adopción de decisiones, implementación y seguimiento, en relación con la Convención" (párr. 28).

Al mismo tiempo, el Comité afirma que "La 'participación plena y efectiva' (art. 3 c)) en la sociedad se refiere a la colaboración con todas las personas, incluidas las personas con discapacidad, a fin de que sientan que pertenecen a la sociedad y forman parte de ella" (párr. 27), reconociendo que "La participación plena y efectiva debería entenderse como un proceso y no como un acontecimiento puntual aislado " (párr. 28). En consecuencia, "Todas las personas con discapacidad, sin exclusión alguna en razón del tipo de deficiencia que presenten, como las personas con discapacidad psicosocial o intelectual, pueden participar eficaz y plenamente, sin discriminación y en igualdad de condiciones con las demás" (párr.16).

The Convention on the Rights of Persons with Disabilities also emphasizes the importance of participation in its articles on enforcement and monitoring mechanisms (arts. 4, 33, 34, and 35) and on international cooperation (art. 32). Faced with all recognized rights, it is the State, in its role as guarantor, who must promote accessibility and participation in the enjoyment of Rights through government management.

The States must generate comprehensive policies to favor the full participation of persons with psychosocial and intellectual disabilities. The constitutive elements of these policies characterized under an ethical floor of Human Rights must inevitably involve citizen participation, *not* induced by the State. Train the different sectors in the transversality of the CRPD. Ensure adequate dissemination of information for the full exercise of citizen rights. The slogan "Nothing About Us Without Us" is an operational legal mandate and that is why we affirm that the participation of the direct protagonists is the fundamental tool in the consolidation of more respectful and inclusive policies, and thus, in their effective compliance.

Equal participation and full inclusion is the principle that runs through the Convention as it is the foundation, mandate, and interpretative criterion of its legal norms (Article 3); the inescapable scope of its expression is found in the concept that persons with disabilities have the right to exercise their freedom, decision-making and, therefore, legal capacity.

Reflecting on this, Sessarego has analyzed the relationship between capacity and freedom, saying that: "Just as there is only one freedom, there is also only one capacity. What happens is that both freedom and capacity are presented to us in two instances or moments. The first is subjective. As for freedom, this moment represents the power of the person to decide for himself. This decision, in which freedom consists, occurs in the field of pure subjectivity, so it is not externalized. As regards capacity, the subjective moment is that of the pure aptitude that every human being has, as such, to enjoy all the rights inherent in his nature as a human being. All men are equally free and all also have the same capacity for enjoyment. This capacity, which is a mere potentiality, belongs to the intimate world of the person. An ontologically free being possesses, naturally, the aptitude to carry out all the necessary acts to fulfill his life project. The human being has the innate aptitude or capacity to decide between an infinite range of existential possibilities. Freedom and the capacity for enjoyment are indissoluble, inseparable elements." The discussion takes place in the restriction of capacity in the face of decision-making, and this is when the Convention on the Rights of Persons with Disabilities has responded to the concept of legal capacity within the social model of disability that has been visualized in Article 12, when it recognizes the right to exercise legal capacity on an equal footing with others in relation to persons with disabilities.

> The gateway to the legal discourse is the recognition of the capacity, In effect, in order to be the holder of rights and obligations it is necessary to have recognized legal capacity. This is generally held, due to the fact of being a person, although at this point there is usually a difference between legal capacity and capacity to act. The former, as I have just pointed out, is linked to being considered as a person; the second, on the contrary, implies possessing a series of traits, among which the capacity to carry out free and responsible conscious acts stands out. These references that determine what is understood by capacity in the ethical and legal fields are a consequence of the very idea of Human Dignity, as it has been constructed from its origin (in modernity) to the present day and that is presented as an argument justification of the rights.

The dynamics of their life plans is the achievement of a dignified human life where the person feels that they are part of the social nucleus through an active life of their own, with an enabling environment for human diversity.

In relation to the exercise of political rights – also called participation rights – these are recognized for persons with disabilities in the Convention (Article 29) and include persons with psychosocial and intellectual disabilities, with the right to choose and be elected. For its part, the operational aspect of recognition of political rights is found in the human rights contained in the Covenant on Civil and Political Rights in Article 25, where the right of everyone to participate in the management of affairs is established and recognized. This includes the right to vote and hold elected positions, as well as the right to have access to public service under conditions of equality and non-discrimination, in the conduct of public affairs, through civil society organizations, in political parties or constituting or from the organizations of persons with disabilities that represent them at the local, regional, national, and international levels. The right to vote as an act of active citizenship is found in the American Convention on Human Rights (Article 23), social interaction guaranteed by the state through reasonable accommodation and support. This becomes clear when persons have the opportunity to get out of the legal foundation of interdiction and community accessibility in all areas is granted through possible channels for the realization of life. On the other hand, it also establishes the right to participate fully and effectively. In this sense, the obligation for the States is to promote participation, through positive action measures. Article 4, paragraph 3, of the Convention on the general obligations of States, highlights the duty of public authorities to closely consult and actively collaborate with persons with disabilities and the organizations that represent them in preparing of the legislation and policies and in any situation that concerns them – That is, it represents the operation of the slogan *Nothing About Us Without Us*.

Deinstitutionalization

As a result of the aforementioned, the paradigm of substitution accompanied the medical/legal criterion of psychosocial and intellectual disability with institutionalization; even today, there is a model that resists transformation, arguing the benefits of specialized hospitals or institutionalization homes for mental health reasons. Institutionalization appropriates lives and slowly convinces persons subjected to the asymmetry of power existing in the system that the only reality is the one that surrounds them.

So the first possible action in the face of institutionalization is accompaniment, the promotion of skills, the recognition of a complex but non-discriminatory outside, the right to life, just as persons are, that is, respect for their integrity. For this accessibility, there is support among peers, making human rights in small gestures that make life. Listen, communicate, and give support for the organization of persons with psychosocial and intellectual disabilities. Persons have the memory of a unique authority, and their participation depends on the nourishment of their active citizenship. Perhaps the first gesture of deinstitutionalization is the power to choose, stand up to the imposed decisions and be part of the proposals.

For that, they need to have the same life experiences that other persons want. A structural barrier to the inclusion and participation of persons with psychosocial and intellectual disabilities is discrimination which continues to block access to equal conditions in community facilities and services.

Respect for their own leadership, through the exclusive knowledge of their experiences; in this lies, the centrality of the person specifying a difference as a variable of real equality. Public Policies that have an inter-sectoral vision of the State to create a mode of inclusion in residences with the support that persons require. That they have a budget and financing for independent living devices.

Support systems for when the person expresses this way through their preferences, this implies that there is no confusion regarding the choice of them or the content that makes them up. It is vital that we generate support systems with values according to the needs of the person. To provide the support, as well as to determine the type of support that the person would accept or would find useful, an interactive process should always be used. Creative and accessible communication should be fostered, as well as reasonable adjustments/modifications to the usual modes of interaction, in order to establish a good supportive relationship and function adequately within it. Ideally, supportive relationships should be ongoing and "the persons" establish such relationships early, for a future when they may need them. However, support can also be used in the case of operations or specific legal acts, so that persons with disabilities can use the services of doctors, lawyers, notaries, banks, etc., ordinarily when they choose to be self-reliant or not enter into an ongoing supportive relationship. This support, in ordinary contexts, in which persons with disabilities interact with other persons on an equal footing, can be seen as comparable to the required conditions of accessibility in communication and reasonable accommodations.

Reasonable adjustments that imply reconversion of a previous protectionist system and asylum by independent living devices with self-management, co-managed and accessibility to credit on the same foot as other persons. Reasonable adjustments in everything that disrupts the enjoyment of the rights recognized in the CRPD, an example of this is the access to sexual and reproductive rights.

In the same way, it is necessary to establish reasonable adjustments for accessing employment, where the ownership of a pension right does not undermine the fullness of labor law. We could point out that the line is regarding deinstitutionalization, establishing the game to the interdependence of Employment rights • Independent life. • Community inclusion. • Health.

Civil dialogue stands as an effective tool and is valued by the authorities, in the same way that universities and extension programs have activities supporting the participation of persons with disabilities in models of deinstitutionalization and independent living.

Independent Life

Persons with psychosocial and intellectual disabilities require that independent living be promoted in the space where the person with psychosocial and intellectual disabilities has their center of life. The change and the setting are to deepen the conception of the Independent Living model as a concept dynamic, and that is used to indicate that persons with psychosocial and intellectual disabilities have control over their lives, accessibility to opportunities on the same footing of equality, to face their decisions, and to exercise responsibilities, assuming the right to take risks. The participation of young persons with psychosocial and intellectual disabilities in an independent housing project is vital for their subjectivity in a discourse of equal opportunities.

Family members of persons with disabilities require accompaniment to promote the independent life of persons with disabilities.

Article 19 of the CRPD establishes: “The States Parties to this Convention recognize the right, on equal terms, of all persons with disabilities to live in the community, with options equal to those of others, and shall adopt effective and pertinent measures to facilitate the full enjoyment of this right by persons with disabilities and their full inclusion and participation in the community, ensuring in particular that:

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom to live, on an equal basis with others, and are not forced to live according to a specific way of life;
b) Persons with disabilities have access to a variety of home, residential and other community support services, including personal assistance that is necessary to facilitate their existence and inclusion in the community and to avoid their isolation or separation from it;

c) Community facilities and services for the general population are available, under equal conditions, to persons with disabilities and take their needs into account."

Article 19 considers the right to autonomous life and access to services for its realization. In the case of persons with disabilities, the particular situation of exclusion, abandonment and discrimination requires that the term "facilitate" referred to in article 19 be translated into "ensure and promote."

Importantly, the Convention establishes that assistance and support services must be provided within the community.

In general, support is needed to move through life and for persons with psychosocial and intellectual disabilities, the most frequent forms of assistance and support are:

Support among peers, organize and be a protagonist in the construction of an independent living program.

– Community support and independent living: help with personal care, support for the performance of some formal acts. Procedures, etc., according to each person.

Residential support: individual housing, self-managed, or co-managed coexistence housing with a community center. According to the preference and autonomy of the person.

– Support for education or employment.
– Communication support.
– Community access: community benefits, peer support, or organizations of persons with psychosocial disabilities.
– Information and advisory services: professional help, guidance service, and decision-making support.

The person is central: the needs, desires, and aspirations of the persons are the priority of the services. Community-based services allow the person to achieve their goals and are flexible over time according to the individual's needs.

Support is for the person and their environment: it implies that extra help is offered to the person, their family, and their friends to help them live and be part of the community, increasing their resources.

Disability as a social construct: disability is understood through the social model of disability as an experience mediated by social structures and processes.

Comprehensive support: they provide any help necessary to overcome the obstacles that disable you and enable you to have a good quality of life.

The strategies vary according to the greater development of the countries, since in those with structural poverty, the deinstitutionalization processes and, therefore, the programs from the public policies for independent living are often very weak.

In this last element, the provision of services through NGOs that have advantages, specialization, and response capacity is strongly emerging in several countries.

The family cannot always be an assistant or support. Assistance through family members can affect the autonomy and mobility of support due to involvement and the family relationship itself. For this reason, it is necessary for persons with psychosocial and intellectual disabilities to have support independent from their families, when necessary.

It is for this reason that the State must ensure financing and accessibility to the sectors that enable independent living, housing, accompaniment, assistance, employment, health, recreation, culture, sports, etc. The role of the States appears as a guarantor of access to independent life. In other words, the pending issues not yet achieved for the effective inclusion of persons with psychosocial and intellectual disabilities are the current challenge. In view of this reality, the activism of the protagonists in their visibility and unavoidable presence are the axes that are narrowing the existing gaps. This is what gives strength and meaning to the expression “Nothing About Us Without Us.”

Conclusions

The Convention, by defining the universal accessibility model as the real possibility that persons with disabilities can interact with their environment and access goods and services without adaptations or specialized design, produced not only an epistemological change but also change in the most intimate of the structures of the world order of distributions.

The slogan “Nothing about Us without Us” has impacted the organizational structures of the States and the reformulation of the Law, emphasizing legal capacity. There is no full right without the exercise and enjoyment of the recognized right.

Respect for inherent dignity, and individual autonomy, including the freedom to make one’s own decisions, which appears from the preamble and as the first general principle of the Convention; for this reason, Article 12 appears clearly when it headlines: “Equal recognition as person before the law.” Legal capacity imposes decision-making and is the gateway to make irreconcilable any way or means of non-recognition of the person in their actions and preferences.

We can conclude that it is the right to live independently and to be included in the community, to have the opportunity to choose where and with whom to live, on equal terms with others, and not be forced to live according to anyone else’s decisions.

Sustainable Development goals and indicators that expressly mention persons with disabilities are notable achievements of the movement of persons with disabilities at a global level and of the systematic work carried out by the United Nations Committee on the Rights of Persons with Disabilities, supported by the CDPD.

Persons with disabilities are crossing the social fabric, without distinction, and therefore, as inhabitants of a territory and as citizens, regardless of their age or condition, they have the right to broad political and public participation. This has led to the reformulation of the expression: “everything with persons with disabilities.”

It is a result of these conclusions that persons with disabilities should be able to count on a life project with the means to carry out the same project and not be discriminated against on the basis of disability.

Communication about this model should be provided to societies that have been captive under the substitution model so that they can also responsibly promote or enable deinstitutionalization for persons with psychosocial and intellectual disabilities who still continue under systems of asylum and hospital-centric treatment.

The construction of a diverse, complex, decentered, and dynamic world is where the effective participation of persons with disabilities finds its seat through the dynamics of their life plans, speaking on their own behalf in relation to life plans.

In relation to the exercise of political rights, it includes persons with psychosocial and intellectual disabilities, with the right to choose and be elected; it is not only an act of active citizenship but is also a foundation for the development of the legal personality of persons with disability.

Public Policies present an intersectionality of concrete guarantees that make the social dimension of the conquest of rights, establishing the necessary support for their realization.

Deinstitutionalization represents the loss of control of lives and the responsibility for generating active means of social presence in terms of equality among persons without establishing ranges of difference due to disability.

Finally, we can conclude that it is the model of independent living.

It translates into access to Housing, accompaniment, assistance, employment, health, recreation, culture, sports, etc. The role of the States appears as a guarantor of accessibility to independent life.

Legal capacity, the right to rights, full participation, and independent living supported by public policy and citizens organization of persons with disabilities demonstrate the meaning of "Nothing About Us Without Us."

"The interhuman also resides in the recourse of some to the aid of others, before the brilliant otherness of others is trivialized or minimized in a simple exchange of good manners established as" interpersonal "commerce within the customs . . ."

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Advocacy in Inclusive Humanitarian Action

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Contents

Abstract

Disability Advocacy and Activism in humanitarian action is both a voice and a mechanism steering disability-informed and disability-mainstreamed development agendas, legislative and regulatory processes, tools, and innovations to consider political, economic, social, and cultural processes that can propagate equitable, inclusionary, and spatially efficient forms of normativity that *leave no one behind*. The Disability Advocacy and Activism movement leverages from, and partners with, individual actors and the groups they represent, multilateral agencies, governments, and civil society, among other key stakeholders and actors, in progressing the policies, practices, and recommendations set out by international treaties and federal and local legislation, policies, and practices. The ultimate aim is to ensure the Triple Nexus or the Humanitarian–Development–Peace (HDP) Nexus (International Organization for Migration (IOM),

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Operationalizing the Humanitarian–Development–Peace Nexus: Lessons Learned from Colombia, Mali, Nigeria, Somalia and Turkey. (2019). https://publications.iom.int/fr/system/files/pdf/operationalizing_hdpn.pdf) is disability-inclusive and actioned in a way that is proportionately universal, resourcing and delivering of universal services at a scale and intensity proportionate to the degree of need. Proportionate universalism recognizes that universal responses are needed to trigger social and environmental investment and legislative and behavioral changes to reduce the impact of present and future shocks and increase society's resilience, highlighting the needs of those who are perpetually marginalized. Central to this movement is a focus on rights, equity, and inclusion, particularly when concerning persons with disabilities and older persons, as well as, displaced populations include refugees. The latter group is at an increased risk of experiencing further harm and marginalization as a result of multilayered barriers and compounded (often inadvertent) discriminatory and exclusionary emergency response mechanisms, human rights and protection systems, and humanitarian action.

The Challenge

Migration is a megatrend that is reshaping the global landscape with an estimated 1 billion migrants, or one in every seven people globally (World Government Summit Future State 2030, 2016). Migration and forced displacement are focal issues for human rights and the Triple HDP (Humanitarian–Development–Peace) Nexus, influencing both local and global discourse among advocates, policymakers, and practitioners (Nguya & Siddiqui, 2020). As governments and policymakers scramble to understand how these mass movements affect societies and economies, the needs of persons with disabilities and older persons remain largely excluded from strategic and systematic considerations. Few would argue that the need for disability rights advocacy and activism remains imperative since disability and aging are major contributors to the vulnerability of persons in humanitarian settings.

The Context

Recent large-scale humanitarian crises, whether they unfold rapidly (such as the pandemic or the Ukrainian war) or slowly (a number of impacts of climate crisis), have been developing into complex emergencies that have the ability to shut down nations, overwhelm healthcare systems, and catalyze a global economic and social crises. They require unparalleled urgent and coordinated global response that directs political will, commits adequate resourcing, and adopts uncompromising duty-of-care to curtail or prevent unprecedented human suffering and financial ruin. They leave impoverished and marginalized populations particularly vulnerable to shocks, causing disproportionate suffering.

In emergency and humanitarian settings with people fleeing insecurity and violence, the forced displacement of persons with disabilities and older persons often leads to great distress and exclusion, with some being left behind or not surviving the displacement journey. Those who reach humanitarian assistance may risk not being identified in the registration process and consequently face further exclusion due to physical, environmental, and institutional barriers to accessing both essential and specialized services and human rights protection (UNHCR, 2011). This chapter sets out how disability advocates and activists set the agenda to highlight such vulnerabilities and set forth specific actions that governments and other humanitarian actors can take to minimize these risks and vulnerabilities.

Persons with Disabilities in Humanitarian Contexts

Persons with disabilities are estimated to represent 15% of the world's population (World Health Organization and the World Bank, World Report on Disability, 2011). In humanitarian contexts, they form a much higher percentage. At higher risk of living in poverty globally, an estimated 9.3 million persons with disabilities are forcibly displaced as the result of persecution, conflict, violence, and human rights violations in addition to climate-induced migration[1]. Persons with disabilities are known as those who are consistently "left behind," being one of the most marginalized populations in conflict, disaster, and even peacetime settings (United Nations General Assembly, 2016).

> Persons with disabilities "include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."
>
> Convention on the Rights of Persons with Disabilities and its Optional Protocol (CRPD, 2006).

From conflict to natural disasters, humanitarian aid is essential in tackling some of the world's most devastating crises. However, not all people have equal access. Persons with disabilities have the same rights and basic needs as others in situations of crisis and/or forced displacement. However, they often face a multitude of barriers to accessing humanitarian assistance, education, livelihoods, health care, protection, and legal rights. In addition, multiple and intersecting forms of discrimination further exacerbate the situation of persons with disabilities, contributing to the violation of

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[1] International Disability Alliance, Recommendation to Include a Stand-Alone Paragraph on Refugees with Disabilities in the Global Compact on Refugees https://www.unhcr.org/events/conferences/5afbfe0c7/international-disability-alliance-recommendation-include-stand-alone-paragraph.html

their human rights. Persons with disabilities and older persons are among the vulnerable and exposed to multiple, compounding, and intersecting forms of discrimination, exploitation, violence, and sexual and gender-based violence, while at the same time they may be excluded from support and services compared to persons without disabilities (Inter-Agency Standing Committee (IASC), 2019, Women's Refugee Commission, 2014).

When analyzing the risks and barriers to including persons with disabilities in humanitarian contexts and action, barriers lead to exclusion, which persons with disabilities face at a higher level than the rest of the crisis-affected population (DG ECHO, 2019). Through the systematic identification and removal of institutionalized, environmental, and attitudinal barriers as well as the use of enablers such as promoting accessibility and universal design standards to shelter/camps, food distribution points, or acquisition of assistive devices, rehabilitation, and psychosocial support, persons with disabilities will be less at risk and improve their resilience.

The Multiplier Effect (United Nations Office on Drugs and Crime, 2016)

Displaced women with disabilities face TRIPLE discrimination – as women, refugees/displaced persons, and persons with disabilities. Displaced women with disabilities can suffer three times over from the stigma, threats, and barriers, experiencing discrimination based on their migrant/displaced status AND their gender and disability. This can include discrimination, exclusion, and mistreatment in accessing essential services, seeking shelter and housing, and accessing education and health services. In humanitarian contexts, displaced women and girls are also more likely to face health problems – both in transit and at their destinations. They continue to face barriers to health care services, sexual and reproductive health services and family planning, rehabilitation services, medication, and access to assistive devices, which are extremely limited, reducing mobility and thus increasing dependency and vulnerability. The lack of these services is considered one of the leading causes of death, illness, and disability among displaced women, especially those of childbearing age. All displaced people are vulnerable to abuse and exploitation, but displaced women and girls, especially those with disabilities, are particularly at risk. It is estimated that women and girls account for 71% of all human trafficking victims. Lack of accessible shelter, overcrowding in camps, and lack of access to basic services and communications increase the risk of gender-based violence, including sexual violence and child marriage. Moreover, when abuses occur, many displaced women with disabilities lack accessible resources, support systems, and knowledge to seek help.

Beek et al., 2017

United Nations Office on Drugs and Crime (UNODC) (2016).

Despite increasing recognition of and commitment to disability inclusion in humanitarian contexts, reliable data on disability among displaced populations is relatively scarce. A seminal study conducted by Handicap International, now Humanity & Inclusion (HI), (Humanity & Inclusion, Disability in Humanitarian Context, 2015) was based on extensive consultation with 484 persons with disabilities, 118 Disabled People's Organisations (DPOs), and 167 humanitarian actors from Latins America, and the Caribbean, Africa, Asia, and Europe. The research showed that persons with disabilities are strongly impacted when a crisis occurs, with up to three-quarters of people with disabilities affected by a humanitarian crisis reporting that they did not have adequate access to basic assistance such as water, shelter, food, or health care services. Half of the respondents reported not having access to specific care such as rehabilitation and assistive devices. Over half (54%) of the respondents with disabilities stated that they have experienced a direct physical impact, sometimes causing new impairments, while 27% report being psychologically, physically, or sexually abused. Increased psychological stress and disorientation are other effects of the crisis for 38% of the respondents with disabilities. It was also estimated that humanitarian crises currently impact approximately 20 million persons with disabilities, and numbers related to budget allocation also indicate a lack of resourcing, with a meager 1% of aid work budgets estimated to go toward supporting persons with disabilities. This is somewhat verified with nearly all aid workers saying persons with disabilities do not have their needs met in crisis and humanitarian situations.

Older Persons in Humanitarian Crises

Available data, although limited, clearly show that older people are disproportionately represented in disaster-related morbidity and mortality. When emergencies strike, whether due to conflicts or natural disasters and where people are forcibly displaced, older men and women are some of the most vulnerable and neglected. They are at the highest risk for fatalities as they face barriers, threats, and risks in meeting their needs due to their age. Such barriers are similar to those faced by persons with disabilities. Unfortunately, the current reality is that similar to the plight of persons with disabilities, older persons are increasingly inadequately addressed in emergencies and humanitarian crises, as highlighted in the 2016 World Humanitarian Summit stating that there was a need to "correct the neglect of older people (HelpAge International, 2016)." Humanitarian action rarely identifies or addresses the immediate needs of older persons, who remain one of the most vulnerable and neglected groups in crises. Even in cases where the response does identify the needs of older persons, often the resources allocated to addressing those needs are inadequate. This was recently evidenced by both the COVID-19 global pandemic and the Ukraine conflict.

Advocacy for the inclusion of persons with disabilities and older persons needs to reach all actors involved in humanitarian response to catalyze immediate changes that include, but are not limited to, the identification and documentation of short and intermediate needs, securing funding, ensuring accessible and equitable humanitarian response, and establishing coordination mechanisms with outcomes-based interventions that are monitored and evaluated for access and inclusion.

Mental Health Conditions and Psychosocial Disabilities in Humanitarian Contexts

Evidence suggests that displaced populations are at an increased risk of experiencing mental health conditions and psychosocial disabilities. Emergency settings requiring humanitarian action, such as armed conflicts and natural disasters, cause significant psychological distress, such as feelings of anxiety and sadness, hopelessness, difficulty sleeping, fatigue, irritability, anger, and more (WHO, 2022). The burden of mental health conditions and more severe, prolonged psychosocial disabilities among conflict-affected and displaced populations is extremely high, as measured by WHO's review of 129 studies in 39 countries. The study reported that among people who have experienced war or another conflict in the previous 10 years, one in five people (22%) will have depression, anxiety, posttraumatic stress disorder (PTSD), bipolar disorder, or schizophrenia (WHO, 2019). The prevalence of mental disorders such as depression and anxiety is expected to more than double among displaced populations in a humanitarian context. According to WHO's recent review, the estimated prevalence of mental health conditions and psychosocial disabilities among conflict-affected populations at any specific point in time (point prevalence) is 13% for mild forms of depression, anxiety, and posttraumatic stress disorder, and 4% for moderate forms of these disorders. The estimated point prevalence for severe mental health conditions and psychosocial disabilities (i.e., schizophrenia, bipolar disorder, severe depression, severe anxiety, and severe posttraumatic stress disorder) is 5%.

In humanitarian settings, depression and anxiety are higher among women and increase with age, placing older persons at high risk. Women, children, and adolescents are at an elevated risk of common mental health disorders, such as depression, anxiety, and posttraumatic stress disorder (PTSD). Recent estimates place the age-standardized prevalence of mental disorders among displaced populations at 10.8% for depression, 15.3% for PTSD, and 21.7% for anxiety (Scherer et al., 2020). Similar figures are seen among young refugees and people (under 18 years) displaced to European countries, with prevalence figures for depression estimated between 10.3% and 32.8%, PTSD from 19% to 52.7%, and anxiety from 8.7% to 31.6% (Kien et al., 2019). These figures are considerably higher than WHO estimates of common mental disorders among the general global population, at 4.4% for depression and 3.6% for anxiety disorders (including PTSD) (Charlson, 2019), conceivably due to the exposure of various stress factors which affect their mental health and well-being.

People with severe mental disorders can be especially vulnerable during and after emergencies and humanitarian settings as they need access to basic needs and clinical care. A review by Charlson (2019) of the health information system from 90 refugee camps across 15 low- and middle-income countries found that 41% of health care visits for mental, neurological, and substance use disorders were for epilepsy/seizures, 23% for psychotic disorders, and 13% for moderate and severe forms of depression, anxiety, or posttraumatic stress disorder. Based on a systematic review and meta-analysis findings, the researchers estimated that approximately one in five people in post-conflict settings has depression, anxiety disorder, posttraumatic stress disorder, bipolar disorder, or schizophrenia, with an estimated prevalence of 22.1% (95% UI: Unit Interval 18.8–25.7) at any point in time in the conflict-affected populations assessed. The estimates showed a higher prevalence of severe mental disorders (about 5.1% point prevalence in the current estimate compared with 3–4% 12-month prevalence in previous estimates) and a higher prevalence of mild to moderate mental disorders (approximately 17% point prevalence in the revised estimates). The estimated YLDs (Years Lost to Disability) per 1000 people for depression and posttraumatic stress disorder were more than five times higher than the existing global mean burden of disease. Children exposed to conflict also face severe emotional stress resulting in lifelong mental health and psychosocial issues (UNICEF, 2020). Children with mental conditions suffer stigma and discrimination and may be excluded from their communities or exposed to further violence. Mental health and psychosocial support (MHPSS) Is essential for improving children's and adolescents' mental health and well-being in humanitarian emergencies.

One of the priorities is to protect and improve people's mental health and psychosocial well-being, focusing on those who are particularly vulnerable, such as those with pre-existing mental health conditions, older persons and persons with disabilities. However, a significant gap has been the absence of a multi-sectoral, interagency framework that enables effective coordination and identifies beneficial practices (Inter-Agency Standing Committee (IASC), 2007). Achieving this priority required coordinated advocacy leading to action among all government and non-government humanitarian actors. This gap was addressed was addressed in the IN Inter-Agency Standing Committee (IASC) Guidelines on Mental Health and Psychosocial Support in Emergency Settings (Convention on the Rights of Persons with Disabilities (2006)).

Advocating for Change: Global Advocacy and Normative Frameworks

International treaties, laws, instruments, and policy frameworks emphasize the relevance of international law in humanitarian crises (IASC, IASC Policy on Protection in Humanitarian Action, 2016). In particular, the International Humanitarian Law (IHL), International Human Rights Law (IHRL), and International Refugee Law, all these bodies of law provide a legal framework that grounds humanitarian action in internationally agreed principles and standards that affirm the rights of all individuals affected by crises, including persons with disabilities. For instance, the IHL provides general protection to all "without adverse distinction" or discrimination, permitting humanitarian actors to prioritize persons with disabilities. Humanitarian aid must make sure, for example, that shelter, food, water, health care, rehabilitation, and protection measures are accessible to persons with disabilities. Both IHL and IHRL affirm the obligations to protect and ensure the safety of persons with disabilities, keeping in mind that they are at risk of being left behind as they may require adapted evacuation. In addition to the above, specific provisions for persons with disabilities that advocate their inclusion in response to movements of refugees and migrants are noted in both the Global Compact on Refugees (UNHCR, Global Compact on Refugees, 2018) and the Global Compact for Safe, Orderly and Regular Migration (IOM UN Migration, 2018).

International normative frameworks have made concerted and decisive measures to address the rights and needs of persons with disabilities in development. Only recently, however, some consideration has been given to persons with disabilities and older persons in humanitarian crises, including those with refugee status. The Convention on the Rights of Persons with Disabilities (CRPD, 2006) is a treaty binding on states to ratify and affirm that states parties must protect and promote the rights of persons with disabilities in their laws, policies, and practices and must also comply with the treaty's standards when they engage in international cooperation. Broader structural issues needed to support persons with disabilities in humanitarian crises are identified by the CRPD. They include the (a) provision of education for children with disabilities; (b) access to appropriate health care; (c) access to shelter, food, and sanitation; and (d) safety from the risk of harm, including exploitation and physical or sexual violence. However, it is known that emergency settings and forced migration increase the likelihood of exclusion from the barriers that prohibit full access to safe evacuations and humanitarian aid and protection, all of which lead to an elevated risk of exploitation and violence, with women and children being most at risk for trafficking, abuse, emotional violence, and sexualized violence.

Provisions are also set out in Article 11 of the Convention on the Rights of Persons with Disabilities (CRPD) (Convention on the Rights of Persons with Disabilities, 2006) and the Optional Protocol (Convention on the Rights of Persons with Disabilities and Optional Protocol, 2007). Article 11 of the CRPD indicates that "*States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.*" The Article requires state parties explicitly to take all necessary measures to protect and reduce risks for persons with disabilities in situations of risk, including armed conflicts, humanitarian emergencies, and natural hazards.

The 2030 Agenda also stresses that all states need to respect, protect, and promote human rights for all, including persons with disabilities. The Sustainable Goals (SDGs) (UN Department of Economic and Social Affairs, 2018) global framework includes a global commitment "to leave no one behind," as outlined in Goal 96, promoting the inclusion of persons with disabilities in humanitarian action. The Sustainable Goals (SDGs) (UN Department of Economic and Social Affairs, 2018) global framework includes a global commitment "to leave no one behind," promoting the inclusion of persons with disabilities in humanitarian action with Goal 9 calling on societies to build sound infrastructures, particularly in areas affected by disasters. The Sendai Framework for Disaster Risk Reduction 2015–2030 (The Sendai Framework for Disaster Risk Reduction 2015 – 2030, 2015) guiding principles include accessibility, the application of universal design standards, and the participation of persons with disabilities to lead publicly and promote universally accessible response, recovery, rehabilitation, and reconstruction approaches. The framework notes the importance of strengthening disaster-resilient public and private investments, mainly through "building better from the start to withstand hazards through proper design and construction, including the use of the principles of universal design." It promotes an "all of society" approach that includes persons with disabilities, aiming to reduce disaster risks and loss of lives and assets.

The World Humanitarian Summit prioritized and offered "hope for an often-forgotten population: the millions of people with disabilities affected by humanitarian crises (Humanity and Inclusion, 2016)." It afforded a platform to focus representatives of NGOs, states, and funding bodies on the needs of this population, which is made acutely vulnerable during natural disasters and conflicts, and promoted the signing of a new Charter on Inclusion of Persons with Disabilities in Humanitarian Action (Humanitarian Disability Charter (2017)), reaffirming their commitment to upholding the rights and meeting the needs of people with disabilities during an emergency. Signatories promise that their future humanitarian actions will be inclusive of people with disabilities, based on five principles (Humanity and Inclusion, 2016):

1. Non-discrimination and recognition of the diversity of people with disabilities
2. Involvement of people with disabilities in developing humanitarian programs
3. Ensuring services and humanitarian assistance are equally available for and accessible to all people with disabilities
4. Implementation of inclusive global policies
5. Cooperation and coordination among humanitarian actors to improve the inclusion of people with disabilities

Following the Summit in 2018, the UN Inter-Agency Standing Committee (IASC) Task Team on Inclusion of Persons with Disabilities in Humanitarian Action began developing the AISC developed guidelines (Inter-Agency Standing Committee (IASC), 2019) to promote the inclusion and full and effective participation of persons with disabilities in humanitarian action. The guidelines specify the deliberate action in all phases of the humanitarian program cycle to ensure the systematic inclusion of persons with disabilities by national, regional, and international humanitarian actors who are involved in policymaking, coordination, programming, and funding, together with the participation of Organizations of Persons with Disabilities (OPDs). The IASC guidelines assist humanitarian actors and affected communities to coordinate, plan, implement, monitor, and evaluate essential actions that foster the full and effective participation and inclusion of persons with disabilities across all phases of humanitarian action.

Advocating for Change: Strategies to Promote Access and Inclusion

Advocating for the needs of the most vulnerable and marginalized, including persons with disabilities and older persons, has to be strategic and comprehensive across the humanitarian spectrum. Therefore, the legal and policy frameworks, the Charter, and guidelines all converge to ensure that relevant stakeholders (1) align with the International Human Rights and International Humanitarian Laws, the Convention on the Rights of Persons with Disabilities (CRPD), the 2030 Agenda (SDGs), and the Sendai Framework for Disaster Risk Reduction and (2) adopt all necessary measures outlined in the IASC guidelines, among others, to ensure the full inclusion, reducing risk, improving resilience, and increasing protection of persons with disabilities and older persons in situations of risk, including the adoption and implementation of inclusive and accessible policies and programs and promotion of the full and meaningful participation and inclusion of persons with disabilities and older persons in the development of and decision-making processes relating to such actions, across all aspects of the Analytical Model for Vulnerability Analysis (Department of International Development (DIFID), 2019). In line with this Model, advocates need to continually pose the following question:

> What obligations do local and state governments have to respect the rights of all persons, including persons with disabilities and older persons, to protect those rights against barriers and abuses, and to fulfill the rights necessary for them to enjoy a life of dignity and security in humanitarian contexts?

Advocates also need to frame the work from the perspective of the HDP Nexus by holding and promoting the position that protecting these rights is not only a legal obligation but also a matter of extreme public interest and intrinsically linked to human development, social cohesion, inclusion, and peacebuilding.

1. Advocate with governments to remove discriminatory laws and ensure their legal frameworks are non-discriminatory and in line with the provisions of the CRPD:
   – Ensure that migration laws and practices uphold the rights of persons with disabilities and older persons by removing existing laws, regulations, customs, and practices that are deemed discriminatory.
   – The CRPD underlines a requirement for equality and non-discrimination of persons with disabilities and older persons. This outlines a need to offset the impact of impairment, including in the emergency and humanitarian contexts. Accessible information, sign language interpreters, the provision of aids (such

    as wheelchairs and hearing aids), and level access camp settings are clear examples of fundamental adjustments.
  - The disability must not be a reason for denying an immigration application or residency as per Article 18 of the CRPD.
2. Advocate for increased awareness, capacity, and guidance:
   - For many humanitarian actors, a lack of understanding of persons with disabilities and older people's needs or knowledge of addressing the barriers they face is a significant challenge. HelpAge International has developed minimum standards (HelpAge, 2012), technical guidelines, and training material and an Age and Disability Capacity Programme (ADCAP (HelpAge, 2013)) to increase individual and organizational capacity to provide age and disability-inclusive humanitarian response.
   - Promote a coordinated response that, at the global and country levels, UN agencies and national governments are responsible for coordinating humanitarian responses to address the needs of persons with disabilities and older persons. Partnerships are critical, including specialist disability agencies such as Humanity & Inclusion (HI) and the Christian Blind Mission (CBM), members of the Red Cross Movement, including the International Federation of Red Cross and Red Crescent Societies (IFRC) and the International Committee of the Red Cross (ICRC), and mainstream NGOs such as Islamic Relief Concern World Wide and Christian Aid, among others.
3. Advocate for inclusive data collection and research:
   - Persons with disabilities and older persons within populations of the displaced, migrants, and refugees in emergency and humanitarian contexts need to be continually highlighted and represented by reliable and robust data to generate a greater understanding of the elevated risk posed by emergencies and to develop strategies to mitigate such risks.
   - Intersectionality: There is a need for robust and reliable data about the numbers and profile of persons with disabilities – including mental health disorders – women, youth, children, and older persons – in emergency and humanitarian contexts globally. Accurate, reliable data are needed during assessments to respond to their needs. However, there is a critical lack of data regarding the numbers and their characteristics and demographics, the barriers they face, and specific needs regarding age, gender, impairment, location, or living situation. After all, an estimated ten million people are disabled within displaced populations, with around two million experiencing significant difficulties in functioning (Migration Data Portal, 2022).
   - There is a lack of consistency in terminology and methodologies for data collection, cultural differences in definitions and concepts of disability, and lack of training or disability awareness among data collection staff which affect the availability and accuracy of data.
   - Persons with intellectual disabilities and mental illness may have difficulties preparing for interviews and collecting the necessary information. In addition, refugees with hearing or physical impairments may need particular assistance to communicate or overcome barriers.

4. Advocate for a twin-track approach to ensure access to funded mainstream and specialized services:
   - Barriers impede accessibility in physical, transport, and communication infrastructure to facilities and services, including schools, health clinics, latrines, water points, bathing facilities, and food distribution points. Difficulties with physical access and the poor design of buildings, including shelters, affect all aspects of daily life and increase the isolation of persons with disabilities and older persons.
   - Ensure that persons/women with disabilities enjoy equal access to health, education, and social protection policies, including protection strategies for women with disabilities.
   - Specific inclusive services are essential to ensure accessible communication services, assistive devices, mobility aids, and carer support where required.
   - In addition to lack of physical access, mainstream services often either are inappropriate or do not cater for the specific needs of persons with disabilities and older persons. In addition, a lack of specialized evacuation procedures, health care that includes orthotics, hearing devices, pain management and psychiatric medication, psychosocial support, and counseling services is of particular concern.
   - Governments and other stakeholders need to tackle the challenge that displaced and refugee populations face to access health care to improve health conditions.
   - Uphold women with disabilities' right to access sexual and reproductive health care and prenatal care, including deploying mobile health clinics (United Nations Population Fund (UNFPA), 2018) to displacement camps and refugee communities.
   - To identify the protection and assistance needs, relevant partners should ensure a swift and systematic identification and registration of persons with disabilities and older persons, particularly those who cannot communicate their own needs. It is also encouraged to include persons with disabilities and older persons in relevant policies and programs in an accessible way.
   - Funding and donor policy: HelpAge International analyzed over 16,000 humanitarian projects between 2010 and 2014 and found that less than 1% (154) had any activity explicitly targeting older people.[13] To address these gaps, advocates need to work with major humanitarian donors in developing mechanisms for assessing proposals that will ensure persons with disabilities and older people's needs are not left behind.

Conclusion

Persons with disabilities and older persons represent a largely invisible group of individuals who are forced to endure emergencies and humanitarian crises, often being trapped and unable to evacuate or being displaced and leaving their homes and homelands in strongly disadvantaged conditions. Apart from the challenge of surviving the journey, persons with disabilities and older persons encounter several barriers. For example, they may face a lack of accessibility to assistance and protection risks, lack of access to medical care, and insufficient access to assistive technology which could make communication and mobility easier. In addition, persons with disabilities and older persons face an even higher risk of being discriminated against or excluded from receiving appropriate support.

Of the more than 100 million people displaced worldwide, women, children, and youth with disabilities and older persons are often excluded from vital services, including those that address gender-based violence, programs for adolescents and youth, and education on sexual and reproductive health care. There is a dire need to advocate for their inclusion across all pertinent programs and services, including equal access to health, education, and social protection policies, including protection strategies for women with disabilities. Also, strengthening the leadership of organizations of persons with disabilities in humanitarian and development action is imperative to address the needs while improving accountability.

Advocacy for the advancement of international normative frameworks, such as the CRPD, the International Humanitarian Law, the Charter on the Inclusion of Persons with Disabilities in Humanitarian Action, and the Sendai Framework for Disaster Risk Reduction ensures provisions concerning situations of risk and humanitarian emergencies. Combined, they all ensure that, with the involvement of persons with disabilities and older persons in decision making and monitoring and their inclusion in the disaster management policies and monitoring process, persons with disabilities and older persons will be supported, protected, and served on an equal basis with others.

Despite the scale and protracted crises and the scarcity of sustainable resources to fund ongoing humanitarian responses, more must be done to promote the inclusion of people with disabilities within existing emergency and humanitarian aid efforts. Creating an inclusive environment for refugees and displaced persons with disabilities and older persons in humanitarian settings is indeed challenging but undoubtedly imperative. Only from a platform of collective advocacy and coordinated action can we ensure that no one is truly left behind.

Case Study

The International Disability Alliance (IDA) – Global Leaders in Inclusive Humanitarian Action

The **International Disability Alliance** (IDA) is an Alliance of 14 global and regional organizations of persons with disabilities (OPDs), representing over 1100 OPDs from across 182 countries, representing an estimated one billion persons with disabilities worldwide. With member organizations around the world, IDA represents the estimated one billion people worldwide living with disabilities. IDA's core mandate is to both advocate for the rights, and promote the inclusion of, persons with disabilities at the United Nations and support organizations of persons with disabilities to advocate for change locally, nationally, and internationally. With its unique composition, including the foremost international disability rights organizations, IDA is considered by the United Nations System as the most authoritative representation of persons with disabilities on a global level. In the past few years, IDA is increasingly becoming more recognized as the key global interlocutor representing persons with disabilities with the United Nations (UN) system, key donor agencies, and beyond.

IDA promotes its effective implementation of the CRPD through coordinated action by representative organizations of persons with disabilities (OPDs) to ensure compliance of the CRPD at national, regional, and international levels. It works with allies and partners to build the capacity of persons with disabilities and their organizations around the world to advocate for collective rights and to take part in the design and implementation of the policies and practices needed for their realization. The 2030 Agenda and its Sustainable Development Goals are integral to IDA's work to promote sustainable development that is inclusive of persons with disabilities.

IDA's commitment and global leadership in Inclusive Humanitarian Action and Disaster Risk Reduction is unparalleled. The global advocacy platform, led by IDA, calls for inclusive humanitarian action and disaster risk reduction that require the full inclusion and meaningful participation of persons with disabilities and their representative organizations in needs assessments, design, implementation, coordination, monitoring, and evaluation of humanitarian and disaster preparedness and response programs and policies is crucial. IDA is reshaping humanitarian aid and emergency response via the following coordinated interventions:

- Coordinating all actors to promote the **UN Convention and Political Commitments**, thereby ensuring the rights and needs of persons with disabilities in situations of risk and humanitarian emergencies via the UN Convention on the Rights of Persons with Disabilities, the 2030 Agenda for Sustainable Development, the Sendai Framework for Disaster Risk Reduction, the IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action, and the Charter on Inclusion of Persons with Disabilities in Humanitarian Action.
- Co-chairing the development of the **IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action**. The Inter-Agency Standing Committee (IASC) is the UN mechanism responsible for coordinating humanitarian assistance across the UN system, together with mainstream humanitarian actors. In 2016, the IASC established the IASC Task Team on Inclusion of Persons with Disabilities in Humanitarian Action ("Task Team") for a time-bound period (2017–2019) to develop IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action. The Guidelines are designed to assist humanitarian actors, governments, and affected communities to coordinate, plan, implement, monitor, and evaluate essential actions that foster the effectiveness and efficiency of humanitarian action. In 2016, the Task Team was established with a tri-partite co-chairing arrangement comprising the International Disability Alliance (representing DPOs), UNICEF (representing UN agencies), and Humanity & Inclusion (representing humanitarian stakeholders). This co-chairing arrangement

is unique within the IASC structure and reflects the Task Team's commitment to CRPD Article 4.3 and the principle of "Nothing about us, without us." The IASC Task Team is an open coordination mechanism with more than 90 stakeholders across DPOs, mainstream NGOs, UN agencies, and governments.

- Leading **Disability-Inclusive Disaster Risk Reduction**: The sixth session of the Global Platform for Disaster Risk Reduction (GP2019) took place in Geneva, in May 2019. Established as a biennial multi-stakeholder forum by the UN General Assembly, the Global Platform is a critical component of the monitoring and implementation process of the Sendai Framework for Disaster Risk Reduction (2015–2030). The aim of the Global Platform is to review progress, share knowledge, and discuss the latest developments and trends in reducing disaster risk. The outcomes of the Global Platform inform the deliberations of the High-Level Political Forum on Sustainable Development and the UN 2019 Climate Summit from a disaster risk reduction perspective. The Stakeholder Group of Persons with Disabilities: Thematic Group on Disaster Risk Reduction actively engaged in advance of and during the GP2019, with the aim to bring a strong message that disaster risk reduction must be inclusive of persons with disabilities. IDA was represented in the Global Platform by a delegation comprising the following regions.
- Agenda setting in **Disability-Inclusive Climate Action**

To date, the rights of persons with disabilities have received limited attention in the context of the UN Framework Convention on Climate Change (UNFCCC). In the Cancun Agreements, adopted at COP16 in 2010, parties identified persons with disabilities as one of the segments of the population whose human rights are acutely affected by the impacts of climate change (decision 1/CP.16). In the Paris Agreement, the parties further acknowledged that they should, "when taking action to address climate change, respect, promote and consider their respective obligations on human rights," including those owed to persons with disabilities (Preamble). In a number of decisions and reports, UNFCCC bodies have also affirmed the importance of taking into account the needs of persons with disabilities and ensuring their engagement in relation to capacity building, education, awareness, adaptation, and action for climate empowerment. In these provisions, decisions, and reports, persons with disabilities are included alongside other vulnerable groups and are not given special consideration. Moreover, persons with disabilities have not been the focus of specific initiatives to respect and fulfill their rights, such as those that have been created for other groups (e.g., the Indigenous Peoples Platform or the Gender Action Plan). IDA is working tirelessly in enhancing inclusion and participation of persons with disabilities and their representative organizations in climate change mitigation and adaptation as a key priority. In collaboration with members and partners, IDA is pursuing the below activities in Disability-Inclusive Climate Action:

1. Meaningful integration of persons with disabilities in climate-related education, training, public awareness, public participation, and international cooperation in the context of the review of the Doha work program and Action for Climate Empowerment (decision to be adopted at UNFCCC COP-26 in Glasgow).

2. Integration of disability rights language, where appropriate throughout decisions adopted by the UNFCCC COP.
3. Creation of a constituency for persons with disabilities under the UNFCCC. Adoption of a series of decisions by the UNFCCC COP on disability-inclusive climate action, which would include the following:
   (a) Measures to enhance the participation of persons with disabilities in UNFCCC negotiations and in bodies established under the UNFCCC;
   (b) A mandate for the UNFCCC Secretariat to produce a series of technical reports, organize a series of workshops, provide capacity-building to UNFCCC bodies, secretariat staff, parties, and
   (c) observers, and facilitate coordination with other UN agencies, international organizations, state parties, and NGOs to identify, promote, and implement disability-inclusive climate policies and programs.
   (d) Measures for state parties and other actors to fully and effectively integrate disability rights in climate policies and programs at the national, regional, and international levels.
4. The Secretariat of the Global Action on Disability (GLAD) Network presents "an action call and guide to promoting disability-inclusive climate change." The preamble to the 2015 Paris Agreement includes persons with disabilities as one of the populations most acutely affected by climate change. However, subsequent provisions omit disability inclusion as an essential principle in action against climate change. Persons with disabilities remain largely excluded from decision-making processes and plans to address and prevent climate change and the responses to climate-related disasters and emergencies at sub-national, national, regional, and international levels. To address this, the Secretariat of the GLAD Network, in close consultation with and guidance by the GLAD Network's working group on disability-inclusive climate action, presented an issues paper on "Promoting Disability-Inclusive Climate Change Action."
5. On April 29, 2021, the International Disability Alliance, the European Disability Forum, the Pacific Disability Forum, Stakeholders Group of Persons with Disabilities for Sustainable Development, United Nations High Commissioner for Refugees, and International Displacement Monitoring Centre co-hosted an event in the framework of the Humanitarian Networks and Partnerships Week (HNPW) 2021 to discuss the relationship between disability and climate change. As the first one in the history of HNPW, the event focused on the urgent need to build bridges between disability rights, environmental, and climate justice movements to ensure that no one is left behind in the context of unpredictable weather patterns (i.e., drought, hurricanes, and storms). This statement was issued by the International Disability Alliance (IDA) and the International Disability and Development Consortium (IDDC) as COP26 – the United Nations Climate Change Conference. IDA and IDDC are calling on all member states and other actors attending COP26 to ensure that the rights of persons with disabilities are protected, respected, and fulfilled in design, implementation, and monitoring of environmental degradation, and climate adaptation and climate mitigation pledges and policies. Immediate measures must be taken to ensure removing environmental, attitudinal, communication, and institutional barriers hindering

the participation of persons with disabilities in climate action negotiations, processes, and events. IDA's advocacy continues to COP28 with the clear statement that without meaningful inclusion and participation of persons with disabilities and their representative organizations, climate action is missing 15% of our planet's population who have the right, responsibility, and capacity to be part of the solution to this global crisis.

- **Persons with Disabilities in Armed Conflict**

IDA hosted the launch of the UN Special Rapporteur thematic report on disability and armed conflict for the civil society and OPDs in 2019. The International Disability Alliance initiated a joint submission to the Office of the United Nations High Commissioner for Human Rights (OHCHR) on the occasion of the 20th anniversary of Security Council Resolution 1325. Jointly prepared by Humanity & Inclusion, Human Rights Watch, International Disability Alliance, Women Enabled International, and the Women's Refugee Commission, this submission will help promote an intersectional approach to the UN Human Rights Council's forthcoming discussions on the 20th anniversary of a ground-breaking Security Council resolution, focusing on the role of women in ensuring peace and security.

- **Refugees and Internally Displaced Persons with Disabilities**

In 2020, the International Disability Alliance and the United Nations Refugee Agency (UNHCR) signed a Memorandum of Understanding (MoU) to facilitate and frame their collaboration. Building on the unique status of UNHCR as the main coordinator of global refugee response, and IDA as the unique representation of persons with disabilities and their organizations, the MOU initiated a key collaboration toward enhancing equal protection, inclusion, and participation of forcibly displaced and stateless persons with disabilities. According to this MOU, UNHCR and IDA commit to joining efforts and exchanging expertise to actively promote the rights of persons of concern with disabilities and affected communities through a partnership to strengthen the capacity and cooperation between organizations of persons with disabilities and UNHCR HQ, bureaus, and country offices. The expected outcome of this collaboration will be enhanced visibility and respect for the rights of persons of concern with disabilities across the capacity-building, coordination, advocacy, human rights monitoring, and strategic efforts undertaken by both parties.

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Disability-Driven Innovation: The True Future of Work

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Abstract

Disability as a driver of innovation is an underexplored topic. However, it is taking on increased relevance following the COVID-19 pandemic and as we continue to adjust to digital-first communications and hybrid models at work. Several outstanding disability activists and entrepreneurs have written or spoken about disability as a driver of innovation recently, including Haben Girma, Eddie Ndopu, and Diego Mariscal. That said, the need is great for more learning on this critical topic. This chapter aims to compile a wider range of examples of inventions and technologies made possible by the disability community, highlight diverse perspectives from the disability community, and draw recommendations from expert practitioners on the "how" of benefiting from disability-led innovation. Further, this chapter seeks to place disability as a driver of innovation as a trend in the global economy and the future of work. In addition to a literature review and case studies, this chapter includes primary research from either interviews or a survey.

Introduction

Persons with disabilities (PWD) have a rich and impressive history of imagining, producing, and bringing to market impactful innovations that meet a human need while solving a problem. The constraints we face every day are both an incentive and a forcing mechanism to think outside the box and find workable solutions. As Haben Girma – a human rights lawyer committed to advancing justice – wrote, "Disability creates a constraint, and embracing constraints spurs inventive solutions. Our history has numerous examples of people with disabilities leading advances in science, technology and other fields."[1]

There is no lack of case studies to demonstrate how many innovations and inventions we experience every day were created by or for the disability community, even if ableism prevents history books and general entrepreneurial lore from sharing these stories through the lens of disability. Examples of such inventions and innovations include the following: the typewriter, cruise control in vehicles, the phonograph, the ever-popular text function, voice to text options, touch features on your phone, the electric toothbrush, and the Internet. All were designed by people with a disability as part of designing themselves into a built environment, technology revolution, and mainstream culture that did not center their needs. Each product found its way to mainstream acceptance, enjoyed widespread commercial success, and fostered a positive change in how we live our lives. Yet, for most, the origin that these innovations stem from the disability community is lost on history.

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[1] Girma, Haben, "Break down disability barriers to spur growth and innovation," *Financial Times*, September 13, 2017.

Elon Musk, an entrepreneur with Autism Spectrum Disorder, said it best, "When something is important enough, you do it even if the odds are not in your favor." That quote defines the reality of innovators, creative thinkers, and entrepreneurs. Any person who dreams of turning an idea into a reality faces countless challenges – precious little support and encouragement, scant funding, and skeptical buyers – to name a few. This experience is further amplified for the disability community.

Now Is the Moment in History to Transform Workplace Inclusion to Truly Harness the Ingenuity of the Wider Workforce

Because of the COVID-19 pandemic, the nature of work and the idea of "the office" have fundamentally – and forever – shifted. Accommodations that the disability community has championed for decades, such as more flexible working models (working remote to an office, work part time or hours outside of the standard "9–5," and reduced stigma to take time off), are more commonplace for most industries and sectors that are not facility-dependent. The impacts of that change go far beyond a transition to more virtual and hybrid work models. Technology is more deeply embedded into our careers, and centering family care, self-care, and mental health are more commonplace. In addition, we are witnessing the "Great Resignation" in the U.S. In November 2021, a record 4.53 million Americans quit their jobs[2] in pursuit of more money, less stressful roles, or more favorable and flexible working conditions. Many considered the benefits of entrepreneurship for the first time – including many in the PWD population. In fact, as Tom Butcher, Senior Advisor to the Zero Project and Director of ESG at VanEck, a global asset management firm, noted, "Whilst people with disabilities most usually haven't had the opportunity to resign to find better opportunities, because of the 'Great Resignation', that is now a possibility."[3]

Taken together, these developments are creating a moment in time uniquely suited to widespread innovation at all levels of society – from large research institutes to entrepreneurs working in their basements or garages to people who do not have a prior identity with entrepreneurship, and now have greater access to spaces and networks because of COVID-19. Specifically, this moment in time is well suited for PWD, especially those who have been excluded from the workforce in traditional models of full-time, onsite roles. PWD who were only able to work part-time pre-COVID can now work full time because they do not have to exert energy in arranging transportation, do not have to take as much time off for appointments, and can still participate in work even when they are not well enough to go out. The nature of employment has evolved to a place where it plays to the strengths of PWD, adept in working remotely,

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[2] https://www.weforum.org/agenda/2022/01/the-great-resignation-in-numbers-record/

[3] Interview with Tom Butcher, Senior Advisor to the Zero Project and Director of ESG, VanEck, March 25, 2022.

staying socially connected when unable to meet in person, maximizing what can be done with limited resources, general resilience to push through in tough situations, and a willingness to be adaptable in the face of change and uncertainty.[4]

There is an urgency to unlock the best that innovation represents, so it becomes a path to upward social and career mobility for PWD, whether part of a larger organization or as an entrepreneur. As many reading this book know all too well, barriers to meaningful advancement experienced by the disability community are pervasive and immense, and even more so when viewed through intersectional lenses such as gender, sexual expression and identity, and race. We often are consigned to entry-level positions, passed over for promotion, not rewarded with equal pay for equal work, treated more as a compliance requirement than a valuable contributor to the organization, and have limited access to vital services such as health care, skills training, the Internet, and affordable transportation. And, for the 12.6% of the disability community unemployed, and those experiencing the highest unemployment rates in 7 years,[5] employment is luxury for many in the disability community. These realities are in conflict.

The onus is, and should be, on organizations to galvanize the innovative potential of PWD. This onus extends beyond just organizations themselves, but also Venture Capital (VC) firms and investor relations bodies like Nasdaq that influence standards of diversity, such as board diversity. With “The Future of Work” now “the way we work” for many companies and roles in the knowledge economy, we are well poised to permanently transform the concepts of employment and value creation within the disability community. More broadly, if we are to solve the existential threats to our well-being that we face today – climate change, resource scarcity, and outdated and wasteful means of production, to name a few – we must embrace the innovative potential and intersectional identities of every one of us.

The coming pages provide an actionable roadmap with case studies and recommendations to more fully utilize the innovative potential for persons with disabilities, specifically geared toward benefiting from the perspectives of existing employees in larger organizations and taking steps to become a more disability-inclusive work culture generally. The roadmap applies across all sectors of the economy and organizations of all kinds – corporations, research institutes, venture capital funds, and small business incubators, to name a few.

This chapter covers the following topics:

1. The connection between disability and innovation. We will explore the physical, intellectual, and emotional traits that allow people with disabilities to be at the forefront of innovation. By better understanding how people innovate, we can more effectively develop and use their talents.

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[4] “How a post COVID-19 workplace can embrace accessibility – for everyone,” guardianlife.com, 2020.

[5] US Bureau of Labor Statistics (BLS).

2. The current state of innovation in the disability community. What are the opportunities and challenges facing the disability community that are either advancing or hindering its potential to innovate?
3. Case studies. Using case studies of innovations brought to market, we will identify best practices of individuals and organizations able to foster innovation.
4. Actionable recommendations. Building on insights from previous topics of this chapter, desktop research, and input from expert practitioners interviewed for this chapter, we will develop a series of actionable recommendations that are widely applicable across organizations of all kinds.

Literature Review

In reviewing the spectrum of research conducted at the intersection of disability inclusion, innovation, and value creation, we identified four themes around which much of the scholarship has coalesced. For sake of clarity, we use the term "scholarship" very broadly – ranging from published books to peer-reviewed journals to research conducted by public sector entities (such as the United Nations or World Bank) to consultancies to focused pieces of content of less than 1000 words written for publication in news outlets. We believe each form of research is important in advancing greater appreciation of the subject, and thus every effort was made to take a comprehensive approach to our literature review.

Our goal is not to conduct an exhaustive review of published work. Rather, we provide sources for interested scholars and practitioners to learn more, highlight opportunities for future research, and demonstrate where this chapter adds to the existing body of research.

Theme #1: The Business Case

There is a limited amount of published research demonstrating a connection between disability inclusion, innovation, and business value. Starting with its pioneering 2018 study, "Getting to Equal: The Disability Inclusion Advantage,"[6] and continuing with its 2020 study, "Getting to Equal 2020: Disability Inclusion,"[7] Accenture has provided a wealth of data and insights that make the connection between disability inclusion and value creation. Accenture's work also provides case studies of work being done in organizations to foster inclusiveness and innovation while also sharing concrete recommendations for organizations to follow.

Return on Disability, a Toronto-based insights and design firm, produces extensive research exploring the economic potential of disability and the integration of disability into business as a value added to shareholders.[8]

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[6] Accenture, "Getting to Equal: The Disability Inclusion Advantage," 2018.

[7] Henneborn, Laurie, and Jerdee, Chad, "Getting to Equal 2020: Disability Inclusion," Accenture, 2020.

[8] For more information on Return on Disability, visit www.rod-group.com

The World Bank has done impressive work in exploring disability inclusion on a global scale, particularly in the areas of development, poverty eradication, and the connection between education and innovation. It has created a frequently updated page on its website dedicated to disability inclusion issues.[9]

Theme #2: The Market Opportunity

From 2020, no organization has conducted as much research as the Valuable 500 to demonstrate the market opportunities for companies that foster innovation through achieving competitive, integrated employment for persons with disabilities. The Valuable 500 has partnered with organizations such as Accenture, EY, Tortoise, Mintel, and the World Economic Forum to conduct a variety of research papers on the market opportunity for disability inclusion and barriers holding companies back from being fully inclusive and better engaging the disability community.[10]

Global Disability Innovation Hub, a UK-based research and practice center with a mission of "driving disability innovation for a fairer world," has a dedicated section of its website where it shares wealth of research, conference papers, and publications from workshops on topics related to disability and innovation.[11]

Theme #3: Product-Specific Innovation

Thanks to the efforts of thought leaders and active publishers such as Haben Girma and Jonathan Kaufman,[12] journalists such as Shira Ovide,[13] and executives like KR Liu and Eve Andersson at Google and Jennie Lay-Flurrie at Microsoft, there is no shortage of published content showcasing how innovation is creating products that are "just as usable by people with disabilities as they are by the general public."[14]

In their recently published book, *Disability Interactions: Creating Inclusive Innovations*, Catherine Holloway and Giulia Barbareschi of University College of London take on an important topic. They explore how the growing understanding of how people with disabilities interact with technology (known as Disability Interactions, or DIX) is helping foster greater innovation by persons with disabilities and

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[9] "Disability Inclusion," https://www.worldbank.org/en/topic/disability#1

[10] For access to the research by The Valuable 500 and its partners, visit https://www.thevaluable500.com/news

[11] For more information on publications curated by Global Disability Innovation Hub, visit www.disabilityinnovation.com/publications

[12] Kaufman writes a regular column for *Forbes* entitled "Mindset Matters" that is an excellent resource for learning more about technology, innovation, and making workplaces accessible for persons with disabilities to best utilize their talents.

[13] Ovide writes the "On Tech" newsletter for *The New York Times*.

[14] Brownlee, John, "How Designing For Disabled People Is Giving Google An Edge," *Fast Company*, May 23, 2016.

allowing society to "tackle complex issues where disability problems are part of a system that does not have a simple solution."[15]

Theme #4: How-to Guides and Playbooks

Just as there is a wealth of examples of disability-driven innovation, there also are many publications, "how-to guides," and "playbooks" that offer recommendations and steps organizations can take to foster disability-driven innovation and maximize its outputs. Many of the experts and organizations previously cited in this section are actively engaged in developing such materials. Examples include "Six ways to advance disability inclusion in your organization" by Karyn Twaronite of EY. Understood.org and Chronically Capable also offer how-to guides.

Areas for Additional Scholarship

Our landscape assessment of current research and content identified three areas of need for additional scholarship:

1. The Connection Between Disability Inclusion, Innovation, and Company Performance: While Accenture and Return on Disability have produced excellent research, more is needed to prove the business case of disability inclusion. This is not research for the sake of creating more research. Rather, "it is about trust and generating trust," observed Abraham McAllister, an advisor and investment manager. "While one great study goes a long way, humans are averaging machines. Something as complex as disability inclusion needs a lot of validation across many scenarios."[16]
2. Disability Representation and Organization Performance: Sophia Akrum, a freelance journalist, recently wrote an article entitled, "Why a dearth of data is blocking disabled access to the boardroom."[17] Its premise is the lack of self-identification by CEOs and c-suite executives on disability status not only limits upward mobility by persons with disabilities in the private sector but also makes it hard to assess the impact disability inclusion has on organization performance and its ability to innovate. Similarly, The Harkin Institute for Public Policy & Citizen Engagement has found there is little data on disability status of boards of

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[15] Holloway, Catherine and Barbareschi, and Giulia, *Disability Interactions: Cleating Inclusive Innovations*, Morgan and Claypool, 2022, X.

[16] Interview with Abraham McAllister, Managing Director, Index Plus, October 1, 2020, and excerpted from Ludke, Robert, "Solving 'Then What?': Empowering Investors to Achieve Competitive, Integrated Employment for Persons with Disabilities," The Harkin Institute for Public Policy & Citizen Engagement, December 2020.

[17] Akram, Sophie, "Why a dearth of data is blocking disabled access to the boardroom," *Raconteur*, January 31, 2022.

directors in publicly traded companies. C-suite leaders and boards of directors often play an essential role in setting long-term priorities such as capital investments in research and development initiatives and ensuring an organization is innovating for tomorrow rather than reacting to today.

3. The Future of Work and Innovation in the Disability Community: As noted prior, we are experiencing unprecedented demand for the skills and talents of PWD to be exactly what organizations need to be innovative. Jonathan Kaufman wrote in one of his *Forbes* columns, “It’s time for companies to realize that the disability experience by definition is innovation personified. Organizations have to think more broadly of what their current needs are and do a serious audit of the potential dividends that the disability experience can offer for future success.”[18] Failure to ensure that all relevant considerations of persons with disabilities are at the forefront of that “re-thinking” will result in a massive, missed opportunity whose consequences will impact all of society for generations to come.

Our Contribution to This Topic

The purpose of this chapter is to draw a connection between the traits that foster the innovative potential of persons with disabilities, how the workplace can adapt to best utilize those traits, and how that results in better organizational performance. Based on the insights from bringing together those concepts, we will provide recommendations on best practices to be implemented by organizations that prioritize innovation.

Forging the Connection Between Disability and Innovation

The data supporting the size of the disability community, purchasing parity of the disability community, and market size for PWD is staggering. The COVID-19 pandemic and long COVID have only increased these numbers and market opportunity.

Let us start with the basics: What do we mean when we use the term disability? This chapter considers PWD to include neurodiversity, chronic illness, mental illness, learning disability, and physical and mobility-related disability. While estimates vary depending upon the definition of disability used, it ranges from 15 to 25%.[19] CDC states that six of ten adults in the U.S. have a chronic disease and four of ten have two or more.[20] Conservatively, an estimated 1 billion people are PWD globally. In 2018, the purchasing power of working-age adults with disabilities was

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[18] Kaufman, Jonathan, “Mindset Matters: The Future of Work, Disability, And Imagining What’s Next,” *Forbes*, December 3, 2020.

[19] WHO, CDC.

[20] https://www.cdc.gov/chronicdisease/about/index.htm

approximately $490 billion, with $21 billion in discretionary income.[21] Another estimate suggests the PWD population at 1.85 billion, an emerging market larger than China. If one considers the friends and family of the disability community, you add another 3.3 billion potential consumers with a personal connection to disability. Combined, the disability market controls over $13 trillion in disposable income.[22] Disability is the majority minority diversity identity globally, and the only one that cuts across all others (age, gender expression, race, ethnicity, and religion). These numbers are rising, attributed to longer life expectancy due to advancements in technology, biotech, and healthcare, disability acquired from the natural aging process, pandemic stress, long COVID (which is now protected under the Americans with Disabilities Act (ADA), and an increase in chronic diseases like heart disease in low- and middle-income countries. The disability community is the only minority group that anyone can join at any time.[23]

Because disability also represents a dynamic culture and community, simplified definitions can be deceptive. The universal symbol of disability is a wheelchair user. The reality is that 96% of severe disability is invisible, including traumatic stress disorder (PTSD), traumatic brain injury, diabetes, cancer, lupus, Crohn's disease, and fibromyalgia.[24] It also negates that disability can be temporary, permanent, or acquired. For example, in the U.S., childbirth is considered temporary, or short-term disability. And 25%, or one in four people in their 20s in the U.S., will become disabled before reaching retirement age.[25] Racial and ethnic minorities in the U.S. are 1.5–2x more likely to have most major chronic diseases,[26] and estimates show that nearly four of ten Americans identify with a race or ethnic group other than white, and suggest that the 2010–2020 decade will be the first in the nation's history in which the white population declined in numbers.[27]

In addition to a rise in chronic health conditions, an aging population globally also contributes to a rise in PWD. And baby boomers control a lot of wealth.

Born between 1946 and 1964, the baby boomer generation in 2022 ranges between 58 and 76 years old and makes up a substantial portion of the world's population, especially in developed nations. Boomers represent 21.19% of the U.S. population, representing 52% of aggregate spending – making it the wealthiest generation in history.[28] The COVID-19 pandemic has only driven these numbers

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[21] https://www.air.org/sites/default/files/Disabil-Market-InfoGpc-508.pdf

[22] Return on Disability, 2020.

[23] The Arc.

[24] https://www.forbes.com/sites/paulamorgan/2020/03/20/invisible-disabilities-break-down-the-barriers/

[25] https://www.ssa.gov

[26] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3794652/

[27] https://www.brookings.edu/research/new-census-data-shows-the-nation-is-diversifying-even-faster-than-predicted/

[28] https://usa.visa.com/partner-with-us/visa-consulting-analytics/baby-boomers-still-outspend-millennials.html

higher. For example, long COVID, or experiencing one or more lingering symptoms, like chest pain, fatigue, or brain fog, 6 months after catching the coronavirus, is experienced by up to 60% of people with confirmed cases.[29]

With the caveat that we do not discount the loss of life globally or the continued discrimination the disability community faces in COVID protocols, elements of pandemic have been a positive test case for the economy more fluidly adjusting to the functional demands of disability markets – and the realization that these adjustments benefit a larger market than PWD alone. Examples include retailers instituting special hours for PWD and seniors before regular shopping hours and technology companies like Zoom, the video conferencing platform ubiquitous with communicating during COVID, adding features like closed captioning and live transcription.

This pandemic-forced experiment in better serving customers has been so successful that many innovation-driven companies are now remote-first versus "hybrid" or "flex" (LinkedIn, Cisco, Alphabet (Google), and PwC).[30] Accommodations that PWD have championed for decades became actualized due to pandemic by embedding accessibility into all business operations, not just technology or physical spaces.

We have established a growing disability community exacerbated by COVID. What do these trends look like in the workforce? Before COVID, an estimated 30% employees were PWD, 62% were invisible, and only 3.2% disclosed[31] (vs. 76% employment participation for those without disabilities.)[32] We support that disability discrimination is a major barrier to PWD more fully participating in the global economy. And, while substantial barriers to employment exist for PWD, and we believe that we can activate the innovative potential of the 30% of employed PWD with greater ease and momentum than we can remove the stigma that prevents PWD from entering the workforce. The opportunity here is enormous to shepherd in a paradigm shift; disabled talent is already in the workforce, to an extent. Statistically, PWD are not disclosing, which suggests active concealment of disabilities and not harnessing this lived experience to influence product and service design – skill sets and experiences critical to unlocking the growing disability market. How can we better harness the innovation potential of disabled talent already employed?

The next segment explores in greater depth the life cycle connection between having PWD to drive outstanding products and services to attract new PWD talent. In short, we surmise that disabled talent designs better products, offers outstanding service to customers and to the organizations they are employed at, and serves as role models to attract more PWD to continue to harness the ingenuity of disabled talent. As disability design advocate Liz Jackson coined, "we are the original life hackers."[33] For many, innovation is a luxury of time. For PWD, innovation is a matter of necessity and survival. Imagine the influx of new ideas at a company where

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[29] https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2784918

[30] https://www.flexjobs.com/blog/post/companies-switching-remote-work-long-term/

[31] Coqual 2020

[32] https://www.bls.gov/news.release/pdf/disabl.pdf

[33] https://www.nytimes.com/2018/05/30/opinion/disability-design-lifehacks.html

30% of its workforce rechanneled the ingenuity of masking disability and instead applied these traits of creativity, resourcefulness, and resilience to the job itself.

The good news is that, while rare, there are concrete examples of PWD at organizations championing disability inclusion and disability culture in the name of innovation in direct ways. As Microsoft's Chief Accessibility Officer, Jennie Lay-Flurrie says, "I don't want to hear 'special abilities' or 'diverse abilities' or 'different abilities,' it's disability. We are proud of our identity. People with disabilities come to that once they see that they're going to be supported and their disability is not going to be seen as [a negative] — it's going to be seen as a strength that it is and, for me, the expertise that it is."[34] This sentiment does not live in isolation – 75% of disabled employees have an idea that can drive value for their companies.[35]

We will continuously revisit the concept of traits and how specific traits enable people with disabilities to be at the forefront of innovation. By better understanding how people innovate, and where they innovate, we can more effectively connect outstanding talent with market opportunities, attract more PWD, and break the cycle of stigma needed to serve the growing disability consumer base.

Current State of Innovation in the Disability Community

The prevalence of disability, as well as the cultural and environmental factors that impact PWD, looks different globally. Multinational companies have the greatest opportunity for impact because of their global talent networks, incentives to compete for top talent, resourcing, and ability to influence a business culture within and between cultures and economies defied by specific geographic borders.

Challenges: Stigmas, Metrics, and Structures

Around the world, PWD experience a near-universal cultural stigma. Historically, this stigma has presented as eugenics, institutionalization, involuntary sterilization, immigration restrictions, and other direct attacks on the lives of disabled people.[36] This stigma is by far an experience of the past. During COVID in the U.S., we have experienced polices approving or establishing "crisis standards of care" denying treatment to people with disabilities or chronic illnesses specifically because they are disabled or relaxing precautions like mask wearing early in response to business demands and political pressure versus scientific evidence, creating overlapping risks for those at higher risk.[37]

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[34] https://www.geekwire.com/2021/microsofts-accessibility-chief-benefits-closing-disability-divide/

[35] https://www.talentinnovation.org/_private/assets/DisabilitiesInclusion_KeyFindings-CTI.pdf

[36] https://daily.jstor.org/the-rise-of-disability-stigma/

[37] https://www.forbes.com/sites/andrewpulrang/2022/01/31/6-ways-responses-to-covid-19-have-been-ableist-and-why-it-matters/?sh=162e25946129

In short, PWD are undervalued in nearly all cultures around the world and this discrimination exists intersectionally with many other forms of oppression such as sexism, ageism, and racism. It should be of no surprise that for the minority of PWD who are employed, there is little incentive to disclose for fear of discrimination or retaliation.

Without voluntary disability disclosures, we do not have the benefit of metrics to connect disability and disability-driven innovation as a material contributor to the profitability of a company. Corporate perceptions of disability do not translate easily into shareholder value that can be measured in a traditional manner: revenue and cost,[38] and only a small handful of large, well-resourced, multinational tech companies like Google, Apple, and Amazon are acting in material ways to center the opportunities that PWD represent.

Disability-related metrics that are more frequently tracked than innovation, growth, and product sales are connected to compliance, which is logical given that diversity, equity, and inclusion (DEI) work in the modern corporation was born from compliance considerations. In the U.S., workplace diversity training first emerged in the mid-1960s following the introduction of equal employment laws and affirmative action. These new laws prompted companies to stand up for diversity "training programs" to support PWD adjust to working in office settings not designed structurally or culturally for PWD. Not surprisingly, since the DNA of corporate DEI metrics and structured for disability inclusion was not rooted in growth and innovation, we have floundered historically to achieve a paradigm shift from compliance to strategy and innovation. DEI is not structured into business in a way to fully realize the innovative potential of PWD.

Simply put: The incentives for disability inclusion at work are not aligned with innovation. In most countries around the world that have specific quotas and protections for PWD, they are implemented as a hiring quota for compliance purposes and not as a strategy for innovation and growth. The inefficiencies of this design live all over the modern corporation as well, such as DEI reporting in through human resources and not customer- and product-focused roles.

The challenges facing PWD are massive. And, we believe that the opportunities at this moment in time might actually stand up to systemic ableism for the first time in history.

Opportunities

The disability justice movement and disability community are larger, more global, and intersectional than it has ever been before. This is likely because of COVID-19, newly disabled PWD seeking community with long COVID, pandemic forcing people to find community virtually versus in person, and greater event accessibility with a pause on live programming around the globe. It is not a coincidence that TikTok and ClubHouse downloads and use rose dramatically during COVID

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[38] Return on Disability, pg 26.

(though Clubhouse downloads and valuation have not kept up). TikTok experienced a significant increase in popularity during the COVID-19 outbreak in the U.S. with a growth of 180% among 15–25-year-old users.[39] Vital technology platforms have united the disability community across time zones and continents and technology to positively reinforcing the "life hacking" movement and innovative mindset that many PWD typically reserve for home versus office expression. And, these virtual networks of the disability community are channeling their collective voices to spread advocacy further into public consciousness and corporate policy. For example, in the summer of 2021, two wheelchair users, Bri Scalesse and Gabrielle deFiebre, were flying within the U.S. When they arrived at their destination, they discovered that Scalesse's wheelchair was damaged beyond use. When the airline staff were asked about the damage, the customer service they received was abysmal.

Scalesse, a TikTock influencer, filmed the entire event and posted it – where it went viral. It was picked up by major outlets, and investigations were launched into how many mobility devices were damaged daily by U.S. airlines.[40]

It should come as no surprise that PWD, our "extreme users," experience high levels of product dissatisfaction, and therefore, a need to innovate,[41] even if they do not think of themselves as being innovators. Simply put, PWD innovate; they simply do it for personal use versus professional gain since 1) it is a matter of necessity and survival and 2) the incentive does not exist to integrate innovation methodology at work. Getting back to traits, if innovation is born from the need to solve a problem outside the norm and PWD do things in ways that average consumers tend not to think about, we can easily extend an assumption that many PWD are natural innovators, "extreme users" of technology and infrastructure, and resourceful to explore many problem-solving pathways. From the moment disabled people wake up, they have to figure out how to get dressed, how to drive, how to communicate, and how to live in a world that is not build to fit their needs. The mindset of disabled people is innately collaborative and communicative, oriented toward problem solving, good at working with limited resources, and used to overcoming daily challenges.[42]

By broadening the talent pool, organizations can "future proof" themselves while focusing on long-term value creation. "If investors want to get a good rate of return, they are going to invest in companies that are looking forward," said Sasha DeMarino, Client Engagement Director at Turnberry Solutions, a global IT and professional services consulting firm. "They want to find the companies that will never have a resource shortage. The smart companies are the ones that opened up that umbrella and found more people to bring in who can sustain the company for a long time."[43]

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[39] https://www.statista.com/statistics/1207831/tiktok-usage-among-young-adults-during-covid-19-usa/

[40] https://www.businessinsider.com/bri-scalesse-delta-broke-wheelchair-systemic-problem-2021-7

[41] ? find.

[42] Diego Mariscal, https://2gether-international.org/pages/disability-startup-network

[43] Interview with Sasha DeMarino, Turnberry Solutions, March 16, 2022.

Organizational DEI is getting a makeover. In the past 2 years, the rise of disability community and connection in a virtual social landscape coincided with a surge in antiracism protests in response to race-related violence against black and Asian American Pacific Islander (AAPI) people, most notably the murder of George Floyd. On May 25, 2020, Floyd, a 46-year-old black man, was murdered in the U.S. city of Minneapolis by a 44-year-old white police officer. In the one year following his murder, America's 50 biggest public companies and their foundations collectively committed at least $49.5 billion to address racial inequality.[44] While there is great critique about if this promised money was ever invested, and invested meaningfully, there is undoubtedly more workplace dialogue around issues of mental health and trauma at work, as well as a surge in DEI-related roles. Despite COVID-19's effects on the U.S. economy, the number of DEI-related job postings increased by 123% between May and September of 2020.[45] The combination of better resourcing for DEI generally and pressure on workplaces to support difficult conversations about justice, pandemic, mental health at work, and trauma have opened the door for DEI programs to be more human versus compliance centric.

The COVID-19 epidemic has compounded this "DEI makeover," accelerating prior investments in digital accessibility, or "ally work." Accessibility jobs, ranging from "head of accessibility" to "accessibility analyst," are increasing at a rapid pace. The number of job listings with "accessibility" in the title grew 78% in 2021. Such listings had risen 38% in the year between August 2019 and July 2020 compared with the previous year.[46] Digital accessibility has largely been a compliance-driven phenomenon from Web Content Accessibility Guidelines (WCAG) and enforced in the U.S. by the ADA. In a world where COVID-19 forced many out of the office overnight, digital accessibility became a need for all – not just those who identified prior with disability. Relatively simple office equipment like second monitors and headphones were shipped prolifically, to make basic tasks more perceivable, understandable, and perceivable (WCAG principles). This should come as no surprise: 5.9% of Americans experience deafness or serious difficulty hearing, and 4.6% experience blindness or serious difficulty seeing.[47] More specifically, approximately 12 million people 40 years and over in the U.S. have vision impairment, including 1 million who are blind, 3 million who have vision impairment after correction, and 8 million who have vision impairment due to uncorrected refractive error.[48] These issues are most likely present during key years of employment. Expanding accessibility work from legal mandates on website to design to the lived experience of more user-friendly interactions with laptops and monitors has helped pave the way for

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[44] https://www.washingtonpost.com/business/interactive/2021/george-floyd-corporate-america-racial-justice/

[45] https://insights.grcglobalgroup.com/the-history-and-growth-of-the-diversity-equity-and-inclusion-profession/

[46] https://www.wsj.com/articles/more-companies-are-looking-to-hire-accessibility-specialists-11630501200, from LinkedIn.

[47] https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html

[48] https://www.cdc.gov/visionhealth/basics/ced/fastfacts.htm

more disability-related conversations in some workplaces. And for good reason, a study conducted by Accenture, the American Association of People with Disabilities, and Disability:IN found that organizations prioritizing accessibility had 28% higher revenue, and people with disabilities represent the third-largest market segment in the U.S.[49]

The formula of a growing disability community that is better connected through technology and has more opportunities to thrive in the workplace working from home, colliding with increased organizational resourcing for DEI, makes this moment an important juncture for organizations. The future of work is now.

Case Studies

As shared in the introduction, there is no lack of case studies to support the connection between disability and invention and innovation: the typewriter, cruise control in vehicles, the phonograph, the ever-popular text function or touch features on your phone, the electric toothbrush, and the Internet. To that list of case studies, we can add more than a few more including Siri,[50] computing transistors,[51] and audiobooks.[52]

While not universal, there are several themes that tie together many of these case studies:

- The original inventor was working to solve a need personal to them and not part of large, well-funded organizations (even if technology eventually acquired).
- The evolution and wider application of the invention/innovation was not originally perceived of by the inventor themself.
- When we think about the mainstream success of these products, there is no widespread appreciation of the innovations/inventions that credit the disability community.

There are also case studies to support the innovation "misses" of disabled talent being removed from innovation practice; this is what Liz Jackson would refer to a "disability dongle," an elegant and well-intended, but ultimately useless solution to a problem people with disabilities never knew they had. It signals the larger problem of perceiving the disability community as recipients versus active participants in a design process.[53] An example? A stair-climbing wheelchair, which has intention to

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[49] https://www.accenture.com/_acnmedia/PDF-89/Accenture-Disability-Inclusion-Research-Report.pdf#zoom=50

[50] ROD.

[51] PWC, as mentioned https://hearillinois.com/hearing-health-blog/history-of-the-hearing-aid

[52] https://www.nytimes.com/2021/10/14/technology/audiobooks-innovation.html

[53] https://www.cbc.ca/radio/spark/disabled-people-want-disability-design-not-disability-dongles-1.5353131

do good, but in reality, is a terrifying concept for many and less preferred to direct access, like ramps and elevators. The sign language glove is another infamous example, which claimed to translate sign language in real time to text or speech as the wearer gestures. For people in the deaf community, and linguists, the sign-language glove is rooted in the preoccupations of the hearing world, not the needs of deaf signers.[54]

The data largely supports these trends and observations: PWD are actively involved in product development, and their solutions have a positive impact on their lives. Solutions also provide value for nondisabled persons, suggesting a connection between disability and innovation.[55] One explanation for this trend is the idea of PWD being "extreme users,"[56] not considered part of the core customer or user base initially. Then again, does not most great innovation happen at the fringes? Otherwise, it would be repetitive of existing solutions and not actual innovation.

Case studies confirm the contradiction that we have laid out prior:

1. PWD are likely not tapping into their disability "expertise" at work.
2. PWD innovating at home for their own use are disconnected from resources to test, scale, and commercialize.

And, those businesses that do include disability perspectives as part of the design process are more likely to consider functionality and consider physical features versus the broader experiences of disability, like mental illness and neurodiversity.[57] For most workplaces supporting disability inclusion at work through the lens of compliance, the benefits of innovation are not being realized. Disproportionately disability-driven innovation is not commercialized, and where it is groups with greater social mobility (men, those already in business) are more likely to be credited. Unfortunately, women and the disability community are less likely to be credited – the origin story of OXO Products, now Helen of Troy, tell this story well. Founder and designer Betsey Farber, if mentioned as all, is remembered as "the wife with arthritis" and not an entrepreneur in her own right.

There are frustrations, and there are also positive trends solving for the contradiction laid out above. The secret to closing the circle? Recruit PWD to lead and participate in roles throughout the product and customer organizations, leverage community and successful role models to attract disabled talent, and leverage disability-driven innovation for profit and widespread appeal. While it is a tall order, strong examples exist of organizations centering disability as a growth opportunity versus compliance mandate: Google, Microsoft, PepsiCo, Disney, TD

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[54] https://www.theatlantic.com/technology/archive/2017/11/why-sign-language-gloves-dont-help-deaf-people/545441/

[55] Conradie 2017.

[56] ROD.

[57] ROD.

Bank, and Shopify, to name a few in the U.S. and Canada. There are also great role models. For example, Daniel Hajas, Innovation Manager at Global Disability Innovation Hub, got his start in innovation "solving his own problem." As a blind person, one of his earliest works was an electronic refreshable tactile graphics display (a Braille-like display for graphics and diagrams). His work to access information in physics class led to a student-led startup. Today he leverages research into disability innovation.[58]

Recommendations

Overall, we support the need and opportunity for repeatable process and scale to hire people with disabilities because it creates value for recruiting, hiring, and engaging PWD.[59] And, beyond hiring, we argue that earning the trust and truly benefiting from the skills and perspectives of PWD extends into the entire employee life cycle. A positive cycle looks like:

> Disabled talent integrated into all areas of business, design innovative products/services, market includes disability community, more happy customers, company growth, role models attract more disabled talent.

Where organizations break in will depend on their size, business model, industry, attitudes of leadership, resourcing, and cultural, structural, policy, and behavioral readiness.

Let us be clear: While there are increasingly roadmaps to follow if you are a multinational like Microsoft, this positive cycling is far less obvious to achieve as an entrepreneur or small to midsize company. One component is critical – this work lives with organizations, not with PWD. It is an organization's responsibility to create cultures of belonging and meaningful career pathways for all employees, independent of gender, race, gender expression and identity, disability, age, etc. Wherever your organization is on your journey, there are always incremental ways to drive workplace inclusion and benefit from a culture of innovation.

Build Organizations Centering Belonging

Transformational DEI work lives in culture, structure, and policy. No amount of unconscious bias training or compliance-driven hiring quotas can compare to building equity into business processes. Inclusion for the disability community, and all employees, lives in the way people treat each other, the written cultural values and

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[58] Interview with Daniel Hajas, Innovation Manager at Global Disability Innovation Hub, February 14, 2022.

[59] ROD.

policy protections, and the structure of an organization, which includes everything from compensation philosophy to promotion transparency to where in an organization culture or diversity work lives.

1. Begin with integrating disability into definitions of diversity at your workplace, and acknowledging that disability is the majority minority globally – and the only one that encompasses all other diversity identities. Race- and gender-related definitions, protections, and programming are not enough to truly benefit from a diverse talent base.
2. Move DEI from under Human Resources or People Operations to a core business function like Product, Strategy, Commercial, or Office of the CEO. For the majority of organizations supporting DEI work, the budget and head-count exists under the Chief Human Resource Officer or General Counsel. While legal teams should own mandated compliance, value for DEI work by employees and talent prospects are highest when driven by customer need. For example, as of April 2022, at Tile, the VP of Software Engineering heads up DEI. At Clover Health, it lives in the Office of the President under the Chief of Staff. At Sarepta Therapeutics, DEI reports to the CFO within the Corporate Affairs team.
3. Make diversity, equity, and inclusion a performance metric: In 2019, tech company Atlassian redesigned its performance review process to no longer reward “smart jerks” with promotion[60] by making team-building one-third of performance reviews. This was an intentional decision to center equity and inclusion. Several other companies connect corporate goals and manager bonuses to creating cultures of belonging. In 2021, Apple, McDonald’s, and Chipotle Mexican Grill made bonuses partially contingent on measurable progress on gender and racial equity. Alphabet’s Google took a step in that direction, indicating it will include such metrics in executive performance reviews. Microsoft, Intel, and utility FirstEnergy have been doing so even longer.[61]
4. Continue to prioritize flexibility and a remote, distributed workforce for nonfacility-dependent roles. In March 2022, the competing leadership priorities to woo people back to the office versus declaring that no one needs to remote to an office ever again began to play out across the economy. What we do know is that elements of pandemic were advantageous to PWD who did not need to rely on transport to access the workplace and had many more opportunities for access events due to the digital environment. We believe that businesses of all sizes and sectors that continue to prioritize flexibility will have the upper hand in attracting dabbled talent and benefited from disability-driven innovation.
5. Invest in Diversity, Equity, and Inclusion work: While there has been a surge in new DEI hires in the U.S., as well as a trend for Chief Diversity Officers to report

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[60] https://www.atlassian.com/blog/hr-teams/our-performance-reviews-framework

[61] https://fortune.com/2021/04/06/corporate-diversity-and-inclusion-linked-to-ceo-pay-nike-apple-mcdonalds-chipotle-google-uber-microsoft-intel-firstenergy/

directly to the CEO, the reality is that existing DEI roles have been underfunded, and underappreciated for a long time. Only 34% DEI professionals hold a senior-most role, and only 28% are fully dedicated to DEI work, indicating a lack of resources and commitment from the top to allow for full-time focus.[62]

Integrating Disability Inclusion into VC Funding and Board Diversity

Larger organizations and corporate entities have a large role to play. But we cannot consider building inclusive organizations and potential for innovation without looking at data for startups. The pandemic disrupted the economic status quo in many unexpected ways over the past 2 years, a top benefit being the explosion of new business applications that began taking shape in the summer of 2020. Nearly 5.4 million applications were filed to form new businesses in 2021 in the U.S. — the most of any year on record, based on the latest data from Census Bureau's Business Formation Statistics.[63] As Tamara Giltshoff says, it should not just be corporates driving innovation. For disability-driven innovation, we need more accelerators and university-based technology hubs, and networks of incubators and accelerators.[64] The funding requirements of VCs have long driven early inclusion at startups.

Create a Culture to Seize the Market Opportunity of Disability-Led Innovation

As previously covered in this chapter, there is a massive market opportunity for mass consumption of products innovated with disability considerations at their core. Companies that are able to bring together people with a variety of lived experiences – disabled and nondisabled alike – are able to innovate at a scope and scale far beyond that of organizations with a homogenous culture. As Caroline Casey, the Founder and CEO of the Valuable 500, remarked, "I'm 50 years old. If I was to innovate about something with a bunch of Irish white women, we would only have one point of view. But I'm not sure how we can problem-solve with such a narrow perspective. It doesn't matter how great talent is. Without different experiences challenging what we believe I am pretty sure that we would create something that only serves 50 year old Irish women. What's the value of that?"[65]

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[62] https://www.webershandwick.com/wp-content/uploads/2019/09/Chief-Diversity-Officers-Today-report.pdf

[63] https://eig.org/news/new-start-ups-break-record-in-2021-unpacking-the-numbers

[64] Tamara Giltshoff, Director, Assistive Technology Impact Fund, Global Disability Innovation Hub, interviewed on February 3, 2022.

[65] Interview with Caroline Casey, Founder and CEO of the Valuable 500, March 28, 2022.

Earn Disabled Talent: Flip the Narrative

Corporate DEI work was born out of a reaction to regulations around affirmative action hiring. Hiring quotas for any diversity identity can be high risk for both the employee and the employer – it is the leaky bucket analogy. It does not matter how many disabled employees we hire to fill a quota; if they arrive, they are not welcomed or given opportunities to thrive, and they leave feeling harmed and losing trust. This is at the detriment to both employees and employers.

1. Disability is a not a bad word. For many, it is a proud culture, community, and identity. Say the word out loud 10, 50, and 100 times until it becomes natural to say.
2. Shift from hiring quotas to structure and building an organization for equity where all employees can thrive. If businesses understand value creation from a product and services standpoint, we need to shift to disabled talent as value creation, not compliance. Recruit disabled talent to every level and function of an organization, not a specific program which can create an "and vs. them" experience as an employee. Customer and product roles can especially benefit from disabled talent for innovation and reaching wider markets.
3. Make accommodations routine and promote access to accommodations: "what do you need to thrive?" is a much inviting experience than not asking the question, or centering the experience around a legal process. Did you know that for the majority of workplace accommodations, 56% are free to execute? The remaining accommodations typically cost USD 500 or less and are products easy to order from an office supply store, like noise canceling headphones or a standup desk.[66] In many countries outside the U.S., "productivity enhancers" is a more common term for accommodations. Prior to platforms like Disclo, there has not been a standardized way to disclose and ask for accommodations at work. There is clearly a need for disruption in this arena when 24,000, 36%, of EEOC lawsuits were disability-related in 2020 and the median cost to defend against disability discrimination lawsuits USD 200,000 K.[67]
4. Champion disabled leaders and employees, across the spectrum of mental illness, neurodiversity, or physical or mobility differences. Role models matter. If you are a disabled leader in your workplace, consider being more public with your relationship to disability. Support the formation of disability-focused employee resource groups, affinity groups, or business resource groups.
5. Mandate inclusive language in job descriptions: This can include everything from gender neutral pronouns, including pay ranges, not requiring advanced degrees or certificate programs (or offering to fund these opportunities as part of the role), and considering the prolific use of ablest language. For example, job descriptions that require that a person be able to lift a certain amount or weight or must have access to their own vehicle can directly discriminate against disabled talent, especially in roles where these requirements are not critical to performance in the role.

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[66] https://askjan.org/topics/costs.cfm?csSearch=2546498_1

[67] https://www.eeoc.gov/newsroom/eeoc-releases-fiscal-year-2020-enforcement-and-litigation-data

Conclusion

"People who live with disabilities bring incredible ideas and creative solutions to the workplace, and I want them at my table." – Wendy Myers Cambor, Managing Director of Human Resources, Accenture (Coqual).

We could not agree more. It truly feels like this juncture in time is momentous for disability inclusion at work. The events of the past 2–3 years, most notably the COVID-19 pandemic, surges of civilian and corporate activism for racial justice, and explosions of new virtual networks, mean that we are witnessing colossal change all which support greater disability-driven innovation. While all of these experiences exist in the ecosystem of ableist corporate culture and wider world, we have made major strides in the last 2–3 years to more fully benefit from the innovation-driven traits that PWD are accustomed to employ in their daily lives, even if not at work.

Most notably, making work-from-home routine has forged greater disability inclusion; many organizations are building resource for their DEI programming and moving toward disability-focused programming through conversations about mental health at work or workplace-based experiences with trauma. Startups are emerging as consulting or staffing organizations centering the culture, perspectives, and talent of the disability community (notably Diversability and the Diversability Leadership Collective, The Valuable 500, C-Talent, Chronically Capable and Disclo, 2gether-International, and Disability:IN. In Canada, Access-can and the Rick Hansen Foundation are also champions for change.)

These gains are because universal forces like politics and pandemic have shifted workplaces by force, not because of any major shift in the quality or availability of disabled talent. Adaptation, resilience, resourcefulness, time management, risk management, creativity, and empathy and compassion have always been traits that PWD embody.

The more workplaces continue to earn disabled talent, the more likely they are to benefit from disability-driven innovation, resulting in higher revenues, profit margins, retention rates, and employee productivity.[68]

The choice for us is clear. Invest in disability-inclusive workplaces to benefit from disability-driven innovation.

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Disability and Aging: A Literature Review on Advocacy and Activism for Sustainable and Resilient Community Living

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Zukiswa Nzo, Tawanda Makuyana, Chino Yabunaga, and
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Contents

Abstract

The book chapter purports to provide insights, research gaps, and lessons using a narrative literature review approach. The discussion was centered on unveiling aging (aging with disability and disability with aging included) advocacy and activism for living arrangement-instutionalized, while taking inspiration from disability movement that is led by disabled people that adopted independent living as an example of community living. The discourse discovered that advo-

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cacy on aging began in the 1970s, while oriented toward feminism; however, the twenty-first century fosters social innovation as well as learning from independent living, thereby making the chapter to foster the idea of giving options for the aging population to choose preference on living arrangements that enhance freedom and dignity as essential human rights.

Keywords

Ageing and disability · Independent living · Sustainable and resilient community living · Empowerment · Sustainable socioeconomic participation and development · Advocacy and activism

Introduction

The purpose of this chapter is inspired by approaches from the activism and advocacy of disabled people to inform aging activism and advocacy for effective use of existing data to strengthen evidence-based policy and program development. The chapter provides the reader with a comprehensive background to understanding current knowledge while highlighting the significance of new dimensions that emerge from insights, gaps, and lessons for community living as informed by advocacy and activism in developing and developed countries. The chapter purports to be a literature review that establishes value, perspectives, and scientific documentation of narrative (activities), both historical and those mushrooming as progressive and contemporary-innovative activism and advocacy geared toward community living of (i) aging with disability, (ii) disability with aging, and (iii) aging while learning from independent living principles applied by disabled people. It is further inspired by a growing call from scholars to ensure that the requirements of this ever-increasing population segment are not ignored by promoting traditional solutions and historical assumptions while extracting value from the population group. Further inspiration of this chapter draws from the heart of the 2030 agenda for sustainable development and its pledge to leave no one behind, paying particular attention to the most vulnerable groups, thereby bringing attention to the need for an intersectional approach based on multiple individuals and environmental characteristics that can hinder effective participation of the aging society such as an older person who has an impairment further facing disablism, added to existing ageism already confronted by.

As background and rationale, literature shows the developed countries' family size as shrinking while exponentially increasing the aging population (Veress & Bagirova, 2018). The United Nations Department of Economic and Social Affairs (UNDESA) report (2017) shows that, globally, the number of persons aged above 80 years is projected to increase more than threefold between 2017 and 2050, resulting from a decline in fertility, improvement in survival, and medical excellence throughout the world. However, the effects of the COVID-19 pandemic brought a need to reconsider responses to aging through advocacy and activism in societies in the global village.

As illustrated in Table 1. While developed countries reveal an inevitable increase in the share of the aging demographics, African countries range from 53 to 75 years (Statistica, 2021).

Table 1 presents the average estimated life expectancy without considering COVID- 19–induced death rate. Taylor and Smith (2017) had an increased concern about the sustainability of the welfare system and the supply of labor. On the one hand, labor unions and governments in developed countries have implemented reforms to encourage people to retire later and employers to hire older workers (Taylor & Smith, 2017). On the other hand, advocacy organizations have enthusiastically promoted the working-longer agenda (Taylor & Smith, 2017). Amid calls to work longer, the availability and quality of paid employees and how those not employed would build and maintain a sense of identity are critical issues that have received little consideration in policy and advocacy on aging and living arrangement. Just as highlighted in Table 1, Australian Treasury's 2015 Intergenerational Report projects substantial change in the composition of its population by 2054–2055; a more considerable proportion of the people will be aged 65 and over, with the number in this age group more than doubling. Labor force participation among people aged over 15 is projected to decline.

The aspects mentioned above affect living arrangements, thereby positioning the chapter to contribute insights toward bringing interventions from an advocacy perspective, as there is a need for careful consideration when responding to the needs of the elderly while taking advantage of their unrealized and overshadowed value to societies (Sorensen & Black, 2001). This chapter focuses on advocacy and activism of disability and aging population groups toward sustainable and resilient community living of the aging population (including aging with disability and disability with aging). The said population groups experience similar challenges in institutionalized Living, requiring similar solutions (Altpeter et al., 2014). On the one hand, Pogach (2019) believes there is a need to give the aging population opportunities to choose between institutionalized and independent living arrangements inspired by the development of the present chapter. On the other hand, consider the global trends that reveal an inevitable increase in movements led by disabled people. At the same time, it has become evident that aging also causes an increase in the number of persons with disabilities, as many would acquire some form of impairment (Robertson, 1999, cited

Table 1 Old age by gender and life expectancy projections

Gender	Developed countries –average life expectancy		Developing countries – average life expectancy	
Male	91.5 years (present)	95.1 years (post-2030)	63 years (present)	76 years (post-2030)
Female	93.6 years (present)	96.6 years (post-2030)	66 years (present)	78 years (post-2030)
Other	–	–	–	–

Source: a compilation from various documents in Sorensen & Black, 2001), thereby raising the alarm to economists concerned with life cycle patterns, production, and consumption; in a welfare state older people do not produce as much as they consume and exert more pressure on the fiscus (Holstein, 2013; Takao, 2009), thus exacerbating the need for sustainable solutions. An explanation of the fundamental definition in this context as follows:

Disability is defined from a social model perspective as a social situation that perpetuates social oppression imposed on people with impairments due to environmental barriers that exclude them from participating in society. Such is entirely distinguished from their impairment (Kazou, 2017). World Health organization's International Classification of Functioning (WHO-ICF) interprets disability as a multidimensional and interactive experience from difficulties in functioning, and arising out of the complex interaction between health conditions, personal factors, and barriers in the physical and social environment (WHO-ICF 2001). Disability comes in because aging people can acquire impairment, while disabled people can grow old. Therefore, based on this social model perspective, this literature will use the terms "persons/people with disabilities" and "disabled people/persons" interchangeably to refer to this population group with functional limitations or impairments which in interaction with environmental barriers hinder their full participation on an equal basis with others (UNCRPD 2006).

Aging is defined as a persistent decline in the age-specific fitness components of an organism due to internal physiological deterioration (Rose et al., 2012). At the same time, ageism is understood as negative and positive stereotypes, prejudices, and discrimination against (or to the advantage of) older adults based on a perception of being senior or elderly (Rose et al., 2012).

Sustainable and resilient community living is, according to Metaxas and Psarropoulou (2021), a combination of words that refers to ensuring dignified living conditions while upholding human rights through creating and maintaining viable options in life. The principle of fairness for present and future generations should be considered in using resources. The chapter presents the methodology, findings, and conclusion as follows.

Methodology

A qualitative research design enabled a narrative literature review strategy to examine the extent of literature. The particular focus was on advocacy and activism and on interconnectedness. The review process considered the chronological and regional scope of the literature from high-ranked academic databases in answering the following questions:

a) What critical thinking around institutionalized and independent living arrangements can enhance sustainability and resilience in community living arrangements?
b) How can movements by persons with disabilities bring social innovation on activism and advocacy for sustainable and resilient community living arrangements for aging with disability and disability with aging population groups?

c) What can be learned from each population group's advocacy to the others for the adoption toward sustainable and resilient community living arrangements while enhancing the socio-economic activeness of the population mentioned above groups?

The researchers conducted a literature search in the following electronic databases: African Journals (Sabinet Online), Emerald Insight Journals, Google Scholar, and Scopus. International, regional, national, and organizational reports, podcasts, publications, campaign materials, social media and websites columns, and personal and unpublished narratives of individuals and organizations concerned (activists and advocates) about aging with disability and disability with aging augmented the scientific documented-scholarly views. Keywords like aging and disability, independent living, institutionalization, sustainable and resilient community living, socio-cultural-economic involvement, and participation were used in the search. A balance of five regional (continental) journals with full text written in English was considered in the present review. A predetermined inclusion of data sources entails (i) published and (ii) unpublished work on activism and advocacy on aging with disability and disability with aging. Exclusion criteria entail activism and advocacy on disabled children, and youth was used in the screening process. The first and second authors independently review each identified data source to determine eligibility and extract study information. The third and fourth authors verified the collected data while refining the chapter to prepare it for publication. Several studies identified, screened, and included or excluded at each stage of study selection shall be established, as shown in Fig. 1. Based on Fig. 1, the researchers retrieved data. They adopted three steps: (a) electronic literature search and screening of research material from the 1970s to 2022, such were augmented with gray literature done using hand searching print, online and social media, and reports of an international organization. (b) Data were extracted and analyzed manually following thematic approach as advised by Miles and Huberman (1994) and in vivo coding (Holton, 2007); based on Saldana (2013), analytical memos were developed, as part of the researchers' reflections concerning the codes, the phenomenon, and their interrelations that distinguished coding from analysis and results. Following Saldana (2013), the memos were based on intuition, reflexivity, and serendipitous occurrences related to disability-skewed independent living. While the coding process and analytical memorizing enable the emergence of patterns in the data, it only enabled and did not determine them as advised by Saldaña (2013). Atlas.ti.8 was used as a computer-aid analytic tool that allowed for immersing data for in-depth analysis and (c) writing the literature review.

Findings

Profiling the Resources Used for the Study

The findings highlight a total of 10,119 academic work, of which 42 met inclusion criteria. Table 2 shows the literature's overview profile on advocacy and activism in developed and developing countries.

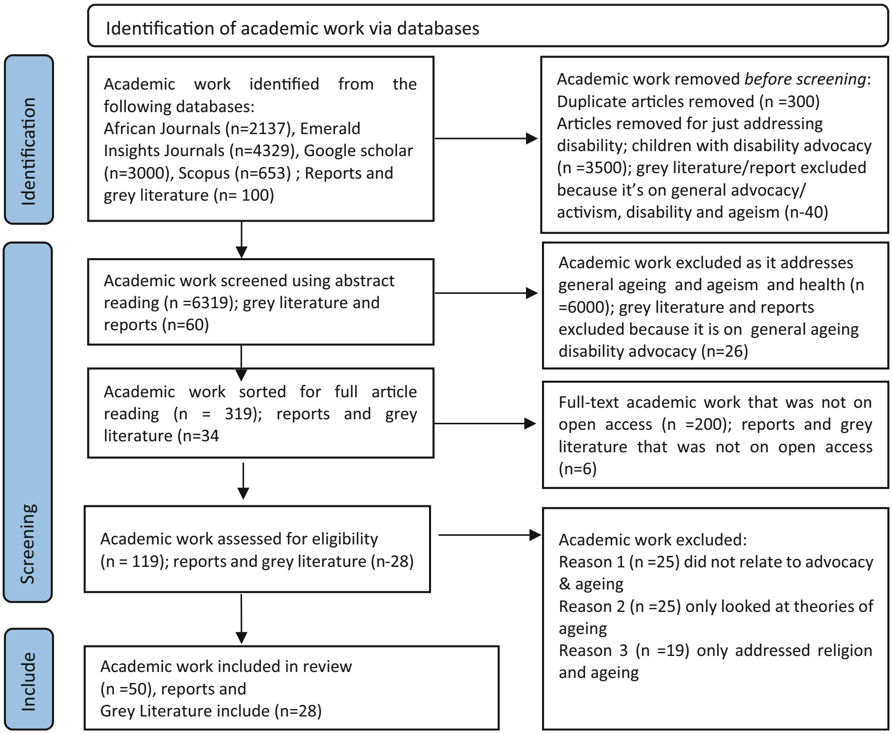

Fig. 1 Data collection and analysis. Source: Adopted in part from Page et al. (2021)

Table 2 shows a dearth of literature on aging advocacy and activism in developing countries, while contrast is observed in developed countries. Literature reflects a difference in demographic composition, social and cultural fabric, economic development, and political systems as determinants in this regard. Despite the differences, there is a shared view on feminism which dominated the rest of advocacy and activism of aging advocacy in all but Japan. The message is skewed on the emancipation of aging women through empowerment and participation in socio-cultural-economic and political spheres. Their voice is equally important as men within the living arrangement.

Literature-Review Discussion

According to Sorensen and Black (2001), advocacy on aging and ageism is dated back to the 1970s as formal, legal, medical-based arguments to probe for changes, where advocacy follows dimensions of (i) self-advocacy, (ii) individual advocacy, (iii) group advocacy, (iv) public interest advocacy provided by paid lawyers, unions, agencies, etc., (v) citizen advocacy by an unpaid citizen, and (vi) systemic advocacy,

Table 2 Overview profiles of results of the review on advocacy and activism on an aging population

Region	Focus areas in the advocacy and activism on aging	Approach used in assessing institutionalized living	Impact/effect and outcome	Lead participants	No. of academic work	No. of gray literature and reports
Developed countries	Japan	Health and social factors	Advocacy for policy reviews; health systems; labor market and employment; involvement, empowerment, and participation in community development	Female aging cohort, lawyers, members of civil society, disabled people led	50	22
	Australia	Health and social factors				
	United Kingdom	Socio-economic factors from a feminist lens				
	Canada	Socio-economic dependence and health factors from a feminist lens				
	United States	Socio-economic independence, dependence, and interdependence using feminist lens				
	Europe					
Developing countries	Still a dearth of literature	Health and social factors	Participation in community	Government and civil society	–	6

Source: Authors' compilation

which is designed to change the system, or laws, policies, procedures, or practices that cause or perpetuate injustice or inequality.

Rationale of Advocacy and Activism

Advocacy

People are not equal, and others are made more vulnerable, with the perceived and actual risk of abuse, than others (Veress & Bagirova, 2018). One such comes from realizing outcomes of advocacy; for example, in South Africa, social rights movements like the anti-Apartheid movement practiced advocacy on a large scale and lobbied for the change in the structures which deny groups of people certain rights based on race, age, (dis)ability, gender, religion, or sexuality. Freedom emerged from such advocacy (Veress & Bagirova, 2018). On the one hand, international organizations like the United Nations General Assembly recognized contributions made by older members of societies and their value to society by announcing 1999 as the International Year of Older People (Veress & Bagirova, 2018), thereby establishing five critical areas to be incorporated into the United Nations Principles for Older Persons (1991, in Office of Seniors' Interests, 1998), namely (i) independence, (ii) participation, (iii) care, (iv) self-fulfillment, and (v) dignity (Veress & Bagirova, 2018).

Activism

Casey (2014) believes activism is an activity that advocacy uses to reach the targeted stakeholders. People interchangeably use advocacy for activism (Casey & Mehrotra, 2011). The chapter regards other related terms which are sometimes used in association with advocacy like campaigning, engagement, consulting, giving voice, negotiating, policy work, lobbying, social action, organizing, and political action, which are used to describe attempts to directly influence (Casey, 2014; Casey & Mehrotra, 2011). Such has the essence of advocacy in some cases (Casey, 2014). Therefore, the current authors bring a historical overview to contextual understanding as presented next.

Historical Overview of Advocacy and Activism on Aging Population

The historical background of advocacy and activism on aging is traceable to multi-cases that highlighted the need for older adults to participate in politics, especially in the era before and post-World War II (Serrat et al., 2021). Charpentier et al. (2008) examined senior women's involvement experience in Quebec, Canada. Their study shed light on family history and continuity in the involvement trajectory, diversity in terms of group type, involvement practices, and gender differences. Unfortunately, the advocacy for the participation of senior women was worsened by the lack of evidence concerning the experience and meaning of their participation from the perspective of those involved, as disaggregated to gender.

As time progressed, Narushima (2004) and Sawchuk (2009) explored social activism by older Canadian women that implicated later life learning, namely the Raging Grannies in Canada. Despite the heterogeneity among "older women," society tends to pathologize them as a part of the "problem" of aging and languishing welfare societies – that is, stereotyped as passive recipients of welfare and healthcare services in Canada (Narushima, 2004). Elderly women can be part of the "answer" to the challenges faced by societies as they have stock of wisdom from indigenous knowledge on strategies, activities, and the process gained from lived experiences through years at work, traveling, and at home (society) (Sawchuk, 2009). Hence activism on ageism led by females dominated the 1970s and 1980s in developed countries like the United States through the Gray Panthers (Ciafone, 2021). Therefore, it furthered the emancipation and representation of old age in US media as correcting ageism. Ciafone (2021) believes that the senior citizens' movement realized the geographical reach, power, and influence of media and, hence, established their Media Watch Task Force and local committees to monitor media and raise awareness on anti-ageism. They conduct media literacy campaigns and even produce their media content to construct an alternative vision of aging. According to Ciafone (2021), the mid-1980s witnessed a change that was visible even on television as older women appeared as active, successful, sexual beings – like *The Golden Girls* – leading some to ponder whether there was a representational shift on TV, even a "waning devotion to youth." Ciafone (2021) interprets such to have contributed to the positive reframing of old age overturned portrayals of them as sick, poor, and dependent and contributed to emerging discourses of an old age that could be "successful," "active," self-reliant, healthy, and even sexy (ageism).

Based on the social-contemporary trends at community level, ageism can be transformed by establishing the value of choice, dignity, and independence from the senior citizens' perspectives. Developed countries like Canada still have a mandatory retirement system within the advocacy discourse. That policy debate is monopolized by the premise of "older people" as post-productive service recipients (Sorensen & Black, 2001). Hence, opportunities to utilize the skills and strengths of older people have been limited by structural factors (Sorensen & Black, 2001). In short, older people, regardless of gender, are alienated from the mainstream, while the social roles and cultural meaning of "old age" are neglected (Sorensen & Black, 2001).

Rationale for Advocacy and Activism for Aging Population

No agreed age defines aging as a phenomenon with physiological and social dimensions (Wentzell, 2020; Wiggin et al., 2021); however, various sources are consistent that the minimum years to be considered senior is 50 or above (Wentzell, 2020). Growing older is associated with negative images (Serrat et al., 2021; Wentzell, 2020); these are physiological and social, like retirement from the paid workforce, which may influence changes in earning capacity, status, and involvement in the community (Serrat et al., 2021; Wentzell, 2020). Therefore, ageism has had unfavorable consequences for older people in our society (Serrat et al., 2021; Wentzell, 2020; Wiggin et al., 2021). It generated and reinforced denigration of the aging process and has given rise to negative stereotypes and presumptions regarding the competence of older people and their need for protection (Serrat et al., 2021; Wentzell, 2020; Wiggin et al., 2021). Studies have found that ageism has made it more difficult for older people to find employment and remain valued members of the paid workforce (Martin, 2018; Serrat et al., 2021; Wentzell, 2020; Wiggin et al., 2021). However, the common perception that workers over 60 years of age are less competent than younger workers is more a myth than reality (Martin, 2018). The chapter attempts to discuss elements of advocacy and activism on aging in the context of aging with disability and disability with aging.

Aging with Disability and Disability with Aging Advocacy and Activism

Viljanen et al. (2021) brought data used in aging advocacy. Their study established challenges posed to healthcare and elderly services as multimorbidity associated with institutionalization. Viljanen et al. (2021) assessed chronic conditions among home-dwelling older people with and without dementia. Viljanen et al. (2021) found that the mean age of the participants (n = 820) was 74.7 years. During the follow-up, 328 (40%) were institutionalized. Dementia, mood disorders, neurological disorders, and multimorbidity were chronic conditions associated with a higher risk of institutionalization in all the participants (Viljanen et al., 2021). In people without dementia, mood disorders and neurological disorders increase the risk of institutionalization. This, therefore, implies that risk factors should be recognized when providing and targeting care and support for older people still living at home. The above notion perpetuated institutionalized living as a solution that addressed ageism among senior citizens, thereby bringing the need to explore how disabled people have managed to have a balance in institutionalized and community living from an advocacy perspective, as discussed below. Therefore, it is essential to note that in lessons learned from other population groups, these differences must be contextualized in community living solutions to be considered.

Overview of Advocacy and Activism on Disabled People and Community Living

The present authors used academic and gray literature to show evidence that community living has been part of advocacy and activism which led to its implementation, especially in the United States through the independent living concept, targeting community living of disabled people. In general, advocacy and activism are centered on government-public and private sectors and civil society to uphold the fundamental principles of independent living as (i) control, (ii) choice, (iii) freedom, and (iv) dignity (Doncel-García et al., 2022). It has been documented that the early inspiration for the independent living movement (ILM) was drawn from the African American civil rights movement of the 1950s and the 1960s because of the similarities they share in both discrimination and stereotypes in housing, education, transportation, and employment (Hayman, 2019). Although other social movements such as deinstitutionalization based on the principles of normalization developed by Wolf Wolfersberger, led by service providers and parents of people with disabilities, had been in existence, disabled people led the independent living movement themselves (McDonald & Oxford, 1995). Accomplishments of Independent Living include legislation, control, services, and dignity to individuals. Awareness-raising communities have been cited as the most significant independent living movement principles accomplishment.

> The movement's most significant contribution is that it has given disabled persons a voice in their own future and has fostered a new sense of dignity and pride that for too long has been denied them. This will continue to be its most important contribution in the years to come. (DeJong, 1979)

Indeed, almost two decades later, a Canadian study on the impact of independent living centers on individuals and the community confirmed the spread of independent living centers across the country and impact (Hutchison et al., 1997) where on an individual level, the Independent Living Resources provided a feeling of being empowered, thereby increasing competence and confidence (Lord, 1991) and an increase in community participation (Friedman, 1992).

The Convention was adopted by the United Nations General Assembly on December 13, 2006. As of December 2021, it had 163 signatories and 184 parties, 183 states, and the European Union (United Nations Department of Economic and Social Affairs, 2022). One of the articles that these state countries are obligated to be article 19 on living independently and being included in the community with states: "*States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that: disabled people have opportunity to choose their place of residence, where and with whom they live on an equal basis with others, as they are not obliged to live in a particular living arrangement; neither to have access to in-home, nor residential among other community-based support services, like personal assistance needed to support living, inclusion in the community, prevent isolation and segregation; Community services, and facilities for the general population are available on an equal basis for disabled people as responsive to their needs*" (UNDESA, 2022). Since the first reported independent living center (ILC) in Berkley, in the United States, the country saw an increase to over 400 centers nationally. Other countries like Japan reported over 125 centers; Canada, over 25; Australia over 7; Zimbabwe, 1; and South Africa, 3.

Cases of Advocacy and Activism by Disabled Persons on Community Living

Print Media

In the **United States**, according to Ed Roberts, who is widely known as the father of independent living, the University of California at Berkeley hesitated to admit him when he applied, as he had polio. He managed to get the story out using media and was reluctantly admitted in 1962. In 1972, the Berkeley Center for Independent Living (CIL) was started (John, n.d.).

In 1998, a **Japanese** man born without arms and legs authored the book *No One's Perfect*, which became a third best-selling book a year after publishing and has been noted to have contributed to shaping societies' views toward disability, as expressed by over 10,000 letters that he received from society (Los Angeles Times, 1999).

Public Demonstrations and Protests

On April 5, 1977, disabled people in the **United States** held what was called the 504 sit-ins to demand anti-discrimination regulations on the Rehabilitation Act of 1973, they stayed until May 1 after a review and approval of the regulations, paving way for the Americans with Disabilities Act (New York Times, 2020). The San Francisco contingent of over 100 people entered Health Education and Welfare (HEW) offices and stayed for weeks. In 1978, the rehabilitation act was amended to provide consumer-controlled centers for independent living.

In Japan "Kawasaki Bus Toso" in 1977 emerged after members of Aoi Shiba stopped 78 buses in Kawasaki that had refused to transport passengers using wheelchairs. Aoi Shiba members occupied and lay on the ground in front of buses to protest the denial of transportation. Their defiance was symbolic as the issue of accessibility later played a leading role in the disability movements in Japan (Iwakuma 2011).

On June 27, 2017, demonstrations are still viewed as an effective form of activism; Wheelchair Sports Camp MC Kalyn Hefferman and seven members of the disability rights group American Disabled for Attendant Programs Today (ADAPT) began a sit-in at the US senator's office. The group demanded the senator's vote against the healthcare bill that would replace President Obama's Affordable one; the new measure was scheduled to be voted on that week. During the sit-in, the Senate announced the vote be moved to after the 4th of July (Westword: Activism, 2017). On July 26, 2017, the Senate rejected a proposal to repeal significant parts of the Affordable Care Act without providing a replacement (The New York Times, 2017).

Global United Nations (UN) Observances

In 1983, John Evans left Cheshire Home to live in his own home in a community, which marked the start of the independent living movement in the **United Kingdom**. This change was achieved through a group known as "Project 81" because the United Nations designated International Year for Disabled People (Leeds University, 2003), thereby influencing independent living and deinstitutionalization.

Lawsuits

Attorney John Holland had filed a lawsuit in 1977 on behalf of Atlantis Community against Regional Transportation District (RTD), arguing that approximately one-third of the fleet should be fully accessible to people in wheelchairs. The district court later ruled against Atlantis (Atlantis Community, Inc. v Adams, 1978); Atlantis appealed and settled with RTD, where the transportation agency agreed to retrofit all buses with wheelchair lifts (Hearings Before the Committee on the Judiciary United States Senate, 1996). Congress passed the **Americans** with Disabilities Act in 1990.

Support by Other Organizations, Research, and Position Papers

In 2012 **Moldova**'s government had taken historic steps to move disabled people out of institutions through Regulations HG351 aimed at directing financial resources to community-based care (Open Society Foundations, 2012). Disability organizations in 2020 reported a slow level of deinstitutionalization and provision of social support services. Seven organizations documented a position paper called "Deinstitutionalization of Persons with Disabilities in the Republic of Moldova" (Keystone Human Services, 2020), calling for **European Union** (EU) support for deinstitutionalization in the Republic of Moldova. In 1981, disabled individuals from the **United Kingdom** raised funds to travel to the United States and gain a firsthand understanding of establishing an ILC to replicate in the United Kingdom (Independent Living Institute, 2003).

In 2013, **South Africa**, through a Japanese non-government organization, a Japanese development agency, provided technical and financial support for the development of an ILC in South Africa (JICA, 2013). The process involved supporting South African activists to undergo independent living training in Japan and visit an ILC in Japan and engage with pioneers of the movement. Soon after that, an ILC was established in South Africa. In a South African study on economic costs of disability by the Department of Women, Youth and Persons with Disabilities, the leaders of the ILC reported they had succeeded in arranging for financial support from the Department of Social Development to deploy personal assistants (Department of Women Youth and Persons with Disabilities, United Nations Development Agency, 2022).

Online Workshops

In 2021, the **European** Network on Independent Living hosted webinars on deinstitutionalization to reach a wider global audience and create an opportunity for sharing experiences on independent living and learning globally (ENIL, 2021).

Social Media

National **American** ADAPT Twitter feed has 1700+ followers, with a Facebook page having 1600+ friends. When ADAPT protested Medicaid changes in Washington, DC, in early May, it live-tweeted the proceedings, including about 100 disability activists (Haller, 2011). Since 2009, the Disability Rights Education and Defense Fund (DREDF) has had a YouTube channel with 734 subscribers. One of its videos reached 12,000 views, though this was rare. DREDF's activism primarily takes place in the courtroom and through lobbying and public policy development and has embraced social media (Haller, 2011).

Inclusion International on international disability day in 2021 launched a global report on self-advocates experiences, ideas, and expectations on calling for deinstitutionalization; this video had 428 views at the time of writing of this chapter and was tweeted (Inclusion International, 2021).

In short, disabled people's advocacy and activism on community living was skewed toward independent living through (a) deinstitutionalization, (b) accessible transport, (c) change in attitudes and raising awareness of challenges faced by disabled people, (d) medical aid policy amendments, and (e) control over funds allocated – over the years taken shape through print media. However, in many countries, public demonstrations seem to have had more significant documented impacts as they drew media attention and that of society; public demonstrations have also been prevalent in recent years. Although we have seen several types of reforms that have followed these activists, this chapter is not intending to suggest a direct correlation. Recently, social media became a common platform for activism as online workshops broadcasted via online platforms such as YouTube channels, live Facebook, Twitter, and closed sessions via virtual meeting tools have been observed. Nonetheless, current authors have not found literature that shows the impact of social media and online activities on this advocacy and activism.

Community Living Advocacy and Activism Opportunities on Aging Population

According to D'cruz and Banerjee (2020), the COVID-19 pandemic exposed the aging population's institutional living challenges, presenting an opportunity for community living advocacy and activism toward deinstitutionalization of those who wish to live in the community. D'cruz and Banerjee (2020) believe older adults are at disproportionate risk of severe infection and mortality and are vulnerable to loneliness and social exclusion during the pandemic. Age and ageism can act as significant risk factors during the pandemic that increases perceived and actual risk to the physical and psychosocial burden on the elderly (D'cruz & Banerjee, 2020).

Understanding Institutionalized Living's Setbacks

Doncel-García et al. (2022) acknowledge ageism as being studied extensively in community-dwelling older adults but remains poorly understood in institutionalized older adults. Therefore, they have compared the physical, psychological, and social variables associated with self-reported age-based biases in community-dwelling older adults and those living in nursing homes. Doncel-García et al. (2022) found negative stereotypes of aging and different multidimensional variables. The variables differ between institutionalized and non-institutionalized adults and between men and women (Doncel-García et al., 2022). Doncel-García et al. (2022), as a first comparative study, levels of ageism in older people living in two different social environments provide a framework to combat this type of discrimination. Promising strategies include anti-ageism policies and laws, educational interventions, and increased intergenerational contact to inform advocacy and activism on aging.

Rabuffetti et al. (2022) examined the relationship between age-related factors and postural stabilization performance after a transition movement. They established controlled elements in the experiment as (1) assistance in living (independent living for community-dwelling subjects vs. assisted living for institutionalized subjects in nursing homes) and (2) age of institutionalized individuals by comparing groups with different age ranges. Rabuffetti et al. (2022) found that when comparing age-matched subjects from the two groups, the residents in nursing homes were characterized by a worse stabilization performance: (i) stabilization time more than doubled and (ii) instability increased by 39%.

There was no difference between the two age groups of residents in the nursing homes; however, a potential confounding effect has been identified in the unequal mortality rates between the two groups. Nakagawa et al. (2022) believes that in Asia, particularly Japan, where autonomous decision-making is not traditionally well accepted; little is known about individuals' preferences on where and how they can receive care. Hence, older adults were asked about their desired place of care (facility, home, or other) if confined to bed. Nakagawa et al. (2022) found that individuals' "aging in place" (community living) preferences tend to be considered under the long-term care insurance system; hence individuals' priorities should be shared with families and clinicians when deciding the place of care and as such play a role in advocacy and activism on aging. Noguchi et al. (2022) recruited a study cohort of non-institutionalized older adults from the Japan Gerontological Evaluation Study, established in 2013, and institutionalized older adults. Noguchi et al. (2022) assessed three aspects of community-level social capital (civic participation, social cohesion, and reciprocity). Noguchi et al. (2022) found that living in a community with rich civic involvement and participation in social activities is associated with lower frailty onset among older adults and fosters social participation. Such data are crucial in decision-making and approaches to living arrangements for the aging population.

Lessons from Disability Movement on Community Living – The Independent Living Movement (ILM)

The present authors perceive that advocacy and activism on aging can consider lessons from the ILM. The ILM emerged as an element of the broader disability rights movement in the 1980s and ascribed to the precept that people with even the most severe impairments should have the same choices that every citizen has (White et al., 2010). A primary goal is the right to choose to live independently, using paid personal assistance services, while living in a community, instead of being institutionalized. Independent living advocates for removing all barriers – in public attitudes, transportation, and architecture – that interfere with full community living (White et al., 2010). Eventually, it became a widely accepted model for centers for independent living (White et al., 2010). This, therefore, draws back to the causes for such an approach to be developed, because of shared similarities in experiences between aging population and disabled people, and advocacy and activism seek to bring initiating voices for a change.

Scholars believe the independent living concept was captured in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) because of its position toward enhancing disabled people to live their life "with choices equal to others" (United Nations, 2019). A critical aspect of the ILM philosophy is reframing how we understand disability – from a medical model to a social (or independent living) model (Slasberg & Beresford, 2020). The medical model seeks only to use a medical cure or healing to normalize a person's condition (Slasberg & Beresford, 2020) while ignoring social factors and perceiving disabled people and seniors as lacking and disempowered (DiGennaro Reed et al., 2014). For a long time, the medical model was associated with isolation and segregation through the institutionalization of societal members because of disability and ageism (DiGennaro Reed et al., 2014).

The chapter identified independent living as a noteworthy preliminary point for aging advocacy and activism to learn and contextualize social innovative ways for their living arrangements. Although advocacy and activism on aging and independent living have numerous common areas of interest, the medical versus social model issue has further unified both groups. Both desire access to independence, dignity, and choice – and their collective activism has moved the system forward. Both groups perceive a need to change the primary legislation to make the resources for independent living a legal right for all (Slasberg & Beresford, 2020). But the activism and advocacy to secure the said assertions may face unknown/fear of perceived lack of incentive, motivation, and interest to have computable costs (Slasberg & Beresford, 2020). Perpetuated ignorance among societal members regarding independent living as costing the government and making funding for social care through a budget cease and move to "open cheque" funding produces unfavorable outcomes (Slasberg & Beresford, 2020).

Framing Aging in Advocacy and Activism for Sustainable and Resilient Community Living

Mah et al. (2021) believe older adults want to live at home if possible, even in circumstances that limit their autonomy. The assertion concurs with DiGennaro Reed et al. (2014) that home care services reflect this emergent preference, allowing older adults to "age in place" in familiar settings rather than receiving care for chronic health conditions or aging needs in an institutionalized environment.

Akosile et al. (2021) believe physical activity (PA), fear of falling (FOF), and quality of life (QOL) are fundamental constructs in geriatrics. The interplay among these constructs may vary between community-dwelling and assisted-living older adults (Akosile et al., 2021). However, studies comparing the well-being of community-dwelling older adults with those residing in assisted-living facilities (ALFs) are rare, especially from developing countries. Thus, Akosile et al. (2021) compared PA, FOF, and QOL between assisted-living and community-dwelling older adults and determined the correlations amongst the constructs for each group. Akosile et al. (2021) found that older adults in the ALFs had lower PA and QOL scores with a higher prevalence of FOF than their community-dwelling counterparts. Akosile et al. (2021) suggest that aging in place (community living) ensures better health outcomes than institutionalized aging. Older adults should be encouraged to age in place rather than move into assisted-living facilities (ALFs).

Marengoni et al. (2021) recruited 2571 community-dwelling older adults grouped at baseline according to their underlying multimorbidity patterns. They followed up for six years to test the association between multimorbidity patterns and institutionalization. Marengoni et al. (2021) found that six patterns of multimorbidity were identified. In total, 110 (4.3%) participants were institutionalized during the follow-up (Marengoni et al., 2021). Marengoni et al. (2021) concluded that older persons suffering from specific multimorbidity patterns have a higher risk of institutionalization if they lack formal or informal care. Therefore, interventions to prevent the clustering of diseases could reduce the associated burden on residential long-term care. Formal and informal care provision in community living can effectively reduce the risk of institutionalization. The essence of the above paragraphs provides evidence-based support for aging advocacy and activism to enhance the availability of living arrangement choices and relevant support to their lives.

Conceptualizing a Framework Toward Community Living of the Aging Population Informed by Literature Review

Similarities, Difference, and the Interconnection in Disability and Aging Activism

The authors raised advocacy and activism on aging from different dimensions. However, the discussion established that advocacy and activism on ageism share common ground with a disability based on shared stereotyping, marginalization, alienation, and discrimination, which emerged as less prevalent, according to Gelders (2015), in discussions on disability and ageism. Averill (2012) brought a rural perspective on older adults in the rural southwestern United States and identified themes needing action, including sustained access to prescriptions, transportation solutions for older adults in isolated communities, inadequate access to care, poor infrastructure and coordination of services, scarce assisted-living and in-home care for frail older adults, and barriers related to culture and economics. An interconnection is observed in literature as associated to age, gender, sexuality, rural settings which directly and indirectly align to the state of physical access, legislation, transport, access to services, labor, and stigma (see Fig. 2).

Figure 2 summarizes the literature review outcome by presenting themes that support learning from independent living among disabled people for the same approach that needs to be contextualized for older adults living in communities instead of institutions. Therefore, Fig. 2 is an input to the conceptual framework for the said people preferring to stay in their homes and communities to the institutionalized living arrangement.

Conceptual Framework

The findings upheld the development of a conceptual framework based on similar concerns between disabled people and the aging population that may call for advocacy and activism. In addition, traditional solutions resort to institutionalized living arrangements for both population segments in this regard. The literature examined reflects critical analysis on institutionalized living that informed the researchers to bring independent living as a point to learn in community living advocacy for the aging population. Such can be of value if the existing data are utilized to augment the voice of the affected population groups, however, taking cognizance of interconnection, heterogeneity, and socio-economic inequalities. Figure 3 is a conceptual framework derived from the reflection on literature, showing

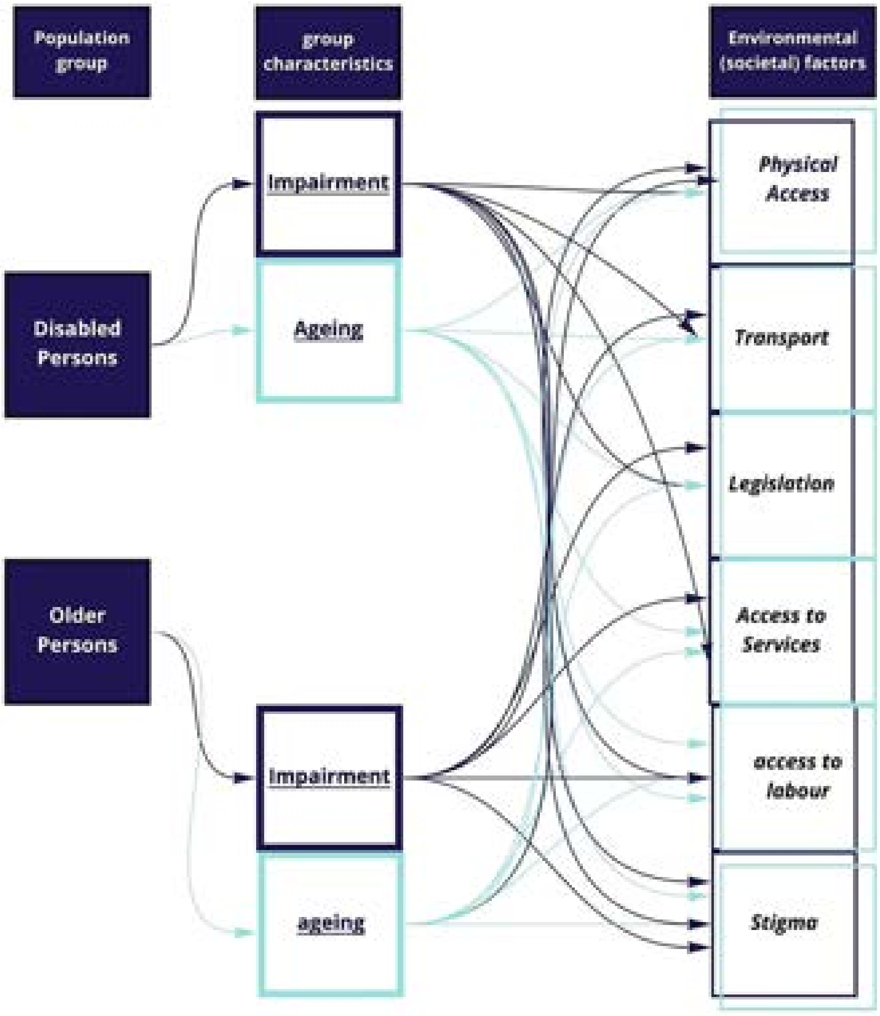

Fig. 2 Disability and aging – the shared similarities and interconnections. Source: Authors' compilation from literature

critical social how interactive factors perpetuating community living arrangement – independent living, impact the following dimensions: (i) individual, (ii) relationships, (iii) community, and (iv) societal levels. When found in institutionalized living, the said elements compromise choices, control, and involvement in decision-making in the said facets. Nonetheless, the review presents advocacy as an enhancer for a similar evolution in the disability movement, to be part of advocacy and activism for aging citizens, as disabled and aging (disability by aging and aging with a disability included) share a societal (socio-economic) negative image,

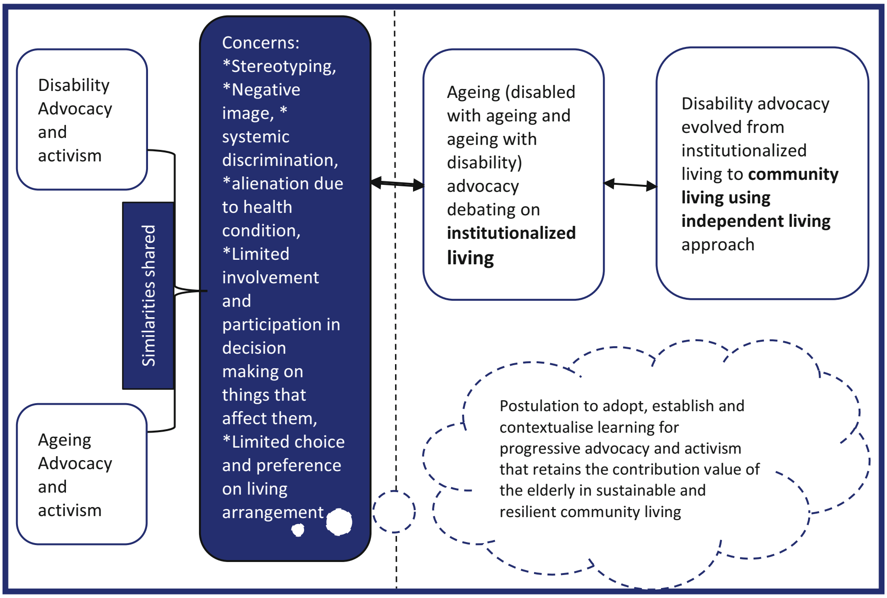

Fig. 3 Conceptual framework toward community living of aging population informed by present literature review. Source: Authors' compilation

stereotyping, and systemic discrimination. Advocacy for independent living regards such people as heterogeneous and hence should have control, choice, decision-making on a preferential living arrangement contextualized to the environment regardless of either growing old or acquiring impairment (see Fig. 3).

Figure 3 presents findings that reflect the need for effort to retain the value of every member of society; however, current solutions contradict this goal. It is clear from findings that costs are reduced with living in communities instead of institutions, coupled with better resilience of health conditions due to improved social interactions. Yet, other countries are undertaking fiscal consolidation reform like their pension systems for cost savings by reducing benefits, while others are in dire need of an increase in the labor force. If advocacy and activism do not use data to inform social action, ignorance and fear of costs on community living will be prevalent.

Conclusion

The chapter presented a consolidation of developed and developing countries' perspectives to enhance and provide the reader with a comprehensive background for understanding current knowledge and highlighting the significance of new research, especially empirical research on addressing interconnecting categories of the aging population beyond impairment characteristics but gender and other factors depending on context. This implies for an aging population to benchmark on independent living movement through, for instance, making plans for physical visits to other centers globally or locally. The chapter encourages the aging population to spearhead activism and advocacy for their voice to be directed to stakeholders like policy-makers while correcting the image stereotyping among other societal members for greater social cohesion in developed and developing countries.

The chapter looked at the *critical thinking around institutionalized and independent living arrangements that can enhance sustainability and resilience in community living arrangements*, where it became clear that ageism, advocacy, and activism on aging share a similar image, stereotyping, marginalization, alienation, and systemic discrimination in line with access and availability of choice and preferences on living arrangements. For freedom of choice, institutionalized living does not have to be eliminated, however solutions towards independence of the aging population should consider their right to choose to participate in the community, and foster innovation due to the value from their experience, wisdom and human capital stock accumulated throughout their life stages. The involvement of senior citizens can enhance a sustainable and resilient community that can exploit the value of aging, which comes with indigenous knowledge systems in addressing life challenges. However, advocacy and activism are vital in changing attitudes (perceptions) and behaviors toward the aging population while considering contextual factors, interconnection, and the choice of the older adult involved.

The aging population's predetermined inclusion and exclusion are influenced by perceived value and perceived costs. However, in addressing issues of sustainability raised by others such as economists, though others have adopted the "working longer agenda," this may not be attained if an enabling environment freely chosen by the aging population is not created. The chapter highlighted challenges posed by environmental barriers that force aging with disability and disability with aging population segments into institutionalized living arrangements. Nonetheless, developed countries have focused on aging and ageism activism and advocacy from the legislative, self, and group to civic dimensions. This contrasts with developing countries, as the two fraternities have different average life expectancy and socioeconomic fabric. In addition, governments are undertaking fiscal consolidation reform like their pension systems for cost savings by reducing benefits, thereby concluding that the aging population prefers to stay in their homes and communities, hence the need for social innovative advocacy and activism, instead of moving to institutions for those who choose to live and participate in the community.

In attempting to address concerns on *how movements led by disabled persons bring social innovation on activism and advocacy for sustainable and resilient community living arrangements for the aging population groups*, the chapter concludes that the disability movement has demonstrated to have a long historical movement aimed at deinstitutionalization and providing choice for living arrangements for disabled people. This group has experience in advocacy and activism geared particularly toward calling for community living, followed by international treaties and legislative reforms, not only on social services and the economic participation of disabled people through employment quota policies and systems and changes in programs and social services. The concept of independent living used by disabled people provides insights for socio-economic innovation in advocacy and activism for the aging population as they share similarities. Such contemporary platforms like social media can be of use to the movements led by aging people while consequently playing a role in shaping advocacy, activism, and implementation of standards set by international organizations.

In addressing *what can be learned from each population group's advocacy to the others for adoption toward sustainable and resilient community living arrangement while enhancing socio-economic activeness of the population mentioned above groups*, in both population groups, it became clear that unless advocacy emerges from the affected parties, decision-makers' ignorance can be perpetuated due to a lack of lived experience-based opinions (voice). Therefore, just as in history, an aging population has demonstrated the capability to advocate for their issues. Hence, the calls for community living should be led by them. Lessons from the disability movement can be considered as the independent living concept is applied in over 500 independent living centers globally. Although there are fewer studies on the impact of independent living centers, those conducted have demonstrated impact on the community and individuals. Guidelines and handbooks on establishing these IL centers already exist in line with the general comments on article 19 on living independently and being included in the community by the Committee on the Rights of Persons with Disabilities in 2017, emphasizing self-representation. However, the existing data are not sufficiently utilized to inform activism and advocacy on aging, causal effects, and impacts of institutionalized living arrangements, and what socio-economic participation could change if community living is enhanced. The chapter was limited because it was developed from desk-top research; hence the authors recommend further empirical research, a longitudinal study that samples developed and developing countries.

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Part XIII

Disaster, Conflict, and Environmental Conditions

Disability, Conflict, and Environmental Conditions: Introduction

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Mary E. Crock and Ron C. McCallum AO

Contents

Abstract

It is now accepted that persons with disabilities suffer disproportionate harms in disaster and displacement contexts, most particularly when persons with disabilities cross international borders in search of protection. Advances in domestic and international laws and policies are changing attitudes and approaches for these people. However, achieving equal treatment and mainstreaming disability-inclusive and rights-based approaches to disaster risk management is a work in progress. The COVID-19 pandemic and ongoing conflicts around the world underscore the importance of the insights provided by the authors in this collection. The shared aim is to lay out a road map to ensuring the full and effective participation of all persons with disabilities in society, acknowledging the intersecting and cross-cutting issues that create barriers in contexts of disaster and displacement.

Keywords

Disability · Disaster · Displacement · CRPD · Functioning · Capabilities

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Introduction

This handbook was written during a period of generational change and challenge. As concern grew about the increasingly obvious effects of human-induced climate change, the world was gripped by a global pandemic. Deaths from the SARS COVID-19 virus and its variants far outstripped the previous ten-year annual average of fatalities attributable to extreme weather and geophysical disasters.[1] In most countries around the world, persons with disabilities suffered disproportionate harm. At increased risk of (fatal) infection, they were also slow to access vaccinations, and more likely to be denied targeted health care and to be treated badly in hospital systems (Lund et al., 2020; Andrews et al., 2021; Matsui, 2021). Secondary impacts of COVID-19 sounded in disruptions in support services as carers fell ill or because of restrictions introduced to restrict spread of the virus (Human Rights Committee, 2020; Lund & Ayers, 2020; ILO 2022). The pandemic serves as a reminder that the human rights of persons with disabilities remains a work in progress.

As the thematic study undertaken by the Office of the High Commissioner for Human Rights (OHCHR, 2020) found, disasters and humanitarian emergencies magnify risks of morbidity and death for persons with disabilities:

> Sudden-onset natural disasters and slow-onset events can seriously affect the access of persons with disabilities to food and nutrition, safe drinking water and sanitation, health-care services and medicines, education and training, adequate housing and access to decent work. (OHCHR, 2020, 3)

The pandemic had an interesting impact on forced migration. The sudden closure of borders brought to a halt both many forms of irregular migration (Ghezelbash & Tan, 2020; Chetail, 2020) and programs for the organized resettlement of refugees and displaced persons (Caraballo, 2020; Bond et al., 2020; UNHCR, 2021). In some countries, there were reports of refugees becoming so fearful of contracting the virus that they chose return to their war-torn countries over staying in refugee camps (The World.org, 2021). In every instance, the impact of the virus on forced migrants – and most particularly those with disabilities – was devastating (Meer et al., 2021; Owen, 2020). The challenges facing relief organizations such as UNHCR, IOM, and the ICRC were extreme and well documented (Martin & Bergmann, 2021; Truelove et al., 2020; Foster et al., 2021; OHCHR, 2020; Crawley, 2021; Hoofman & Goncalves 2020).

In this section, we explore advances in law, policy, and practice that can or should be assisting persons with disabilities to enjoy rights in emergency and disaster contexts. The situations explored by the authors include some of the most extreme faced by human beings anywhere. At the center of our inquiry is the recognition that while cataclysms kill and maim – creating disabilities – they also impact persons already living with disability. As a number of the contributors point out, the assumption that persons with disabilities are underrepresented in

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[1] See https://ourworldindata.org/explorers/coronavirus-data-explorer. Compare CRED (2021), p. 1.

displacement contexts is patently false (xrefs) – even as these people continue to be invisible in much of the data collected about populations on the move. (ref) What is more obvious is that displacement can exacerbate vulnerability in persons with disabilities (Crock et al., 2017; Lund et al., 2020). Kälin notes that the 1992 UN Framework Convention on Climate Change (UNFCCC) acknowledged that climate change would increase displacement in three contexts: forced migration, voluntary migration, and planned relocation of at-risk populations.[2] The intervening years have indeed borne out this reality. The section contributors all argue that an inclusive, human rights–based approach should be adopted in both planning for disasters (including disaster risk reduction) and in humanitarian relief operations (including refugee contexts). International law has now developed to the point where core principles should be beyond dispute (Aleinikoff, 2020).

Outline of Part Chapters

The section begins with a chapter by Professor Emeritus Walter Kälin, UN expert advisor on internal displacement, including human movement in response to disaster and climate change. He identifies as starting points for realizing rights in persons with disabilities: nondiscrimination and equality of opportunity, participation and inclusion, accessibility, and reasonable accommodation (of disability) (ref). His chapter is framed around the argument that

> taking the human rights of persons with disabilities seriously contributes significantly to preventing their displacement, addressing their assistance and protection needs during displacement, and finding solutions ending their displacement in ways that address these needs.

Kälin sets the stage for our analysis by identifying key duties in states – to respect, protect, and provide for persons with disabilities – that act as entry points for human rights–based action that can serve to prevent displacement and/or minimize related harms.

A common theme running through the chapters in this section is acknowledgment of the intersectional relationship between disability, poverty (World Bank GFDRR, 2020), and all the multidimensional elements that underlie discrimination and disadvantage in societies around the world. Overlaying this is the huge variation in disabilities, lived experience (capabilities), and needs. Disability expert and legal scholar Janet Lord (▶ Chap. 88, "Widening the Scope of Non-refoulement? The CRPD and the Protection of Persons with Disabilities in Displacement") notes that the impact of disasters is felt differently by women, children, and older persons with disabilities. Each can face heightened risk (Vidili, 2018). Lord has as her focus Article 11 of the Convention on the Rights of Persons with Disabilities (CRPD). This

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[2] COP16 (2010), para. 14(f).

revolutionary provision crystalizes and affirms the rights of persons with disability to equal treatment in all situations of emergency or disaster, putting aside older understandings that human rights can be suspended when situations become exquisitely challenging (ref). The first to acknowledge rights in the context of natural disasters.

Lord collects and analyzes the way that states, UN bodies and agencies, as well as NGOs and INGOs have responded to Article 11 in word and deed. She describes a

> complex landscape of disability-inclusive disaster cooperation at the international level (which) includes . . . policy guidance and political signals provided by multilateral organizations; informal cooperation among state and non- state actors across levels and across countries in advancing disability-inclusive disaster action and response.... (A)ll play important roles in bolstering, complementing, and implementing Article 11 of the CPRD.

In the chapter by planning lawyer Matthew Cole, Kälin's overview is given context in a case study that examines how inclusive land use planning can help build resilience in persons with disabilities in disaster situations. Cole uses as his starting point the lived reality of these people, affected as they are by multiple and intersecting structural inequalities. Persons with disabilities are more likely to be poor, lack education, and to live in marginal housing, with inadequate access to health care and emergency accommodation. He argues that "disaster justice" acknowledges both the social dimensions of adverse events and the need to mitigate structural inequities as a means of reducing risk of harm. Taking land use planning as a model, Cole draws out elements of the CRPD that focus on equality of access and the merits of "universal design."

Cole sets out the theoretical underpinnings of "just" disaster risk reduction strategies. He explains that risk planning requires an assessment of four types of assets that affect the impact of adverse events. These are described by the theorists as physical, human social, and environmental. Cole uses these to reflect on ways in which planning laws can and should be framed so as to minimize harm and maximize whole of society resilience.

The four chapters that follow take us into particular disaster contexts. The situation facing persons with disabilities displaced as refugees is addressed by legal academic, Professor Mary Crock, Swiss lawyer and advocate Dr Stephanie Motz, and by academic linguist and lawyer Dr Laura Smith-Khan. Crock opens this discussion with an overview of the particular institutional responses to developments in international disability rights law in UN agencies responsible for migrants and refugees, including UNHCR and IOM. Her chapter also introduces the UN Refugee Convention definition of refugee, noting the way in which understanding of the law has altered in response to the CRPD.

Motz extends this inquiry by examining the extent to which the CRPD has created novel obligations under international law not to return persons with disabilities who face expulsion from a host country. Her chapter analyzes jurisprudence from regional and UN treaty bodies on cases involving *nonrefoulement* claims and persons with disabilities. The work is particularly interesting in its review of

European case law because of the ability in European contexts to use human rights law as “hard” law. She critically analyzes the existing *nonrefoulement* case law in light of the medical and the human rights–based models of disability. The chapter demonstrates the impact that the CRPD is beginning to have on international refugee law, migration law, and general human rights law.

Although mentioned by Crock in her survey chapter, the issue of process in refugee law deserves deeper consideration where the person seeking asylum is living with a disability. Dr Smith-Khan examines those provisions in the CRPD that confer “procedural and communication-related” rights in refugees with disabilities. This author summarizes the guidance policies issued by UNHCR that acknowledge the central importance of designing procedures in a way that allows all refugees to articulate their protection claims. Recent years have brought increased understanding of the ways in which refugee status determination procedures can affect a person’s ability to tell his/her story in a coherent way. Smith-Khan makes the case for inclusive and adaptive procedures through a case study of refugees who are deaf or hard of hearing. This is a form of disability that can be easy to miss in the press of high-volume status determination scenarios. Ever grounded in practice, Smith-Khan concludes with a discussion of strategies that can be adopted to ensure that procedures are inclusive and properly adapted to accommodate different forms of disability.

The section concludes with a piece that takes us back to the sweeping disaster of COVID-19. The case study is situated in Kenya and has as its focus upon the rights of women and girls with disabilities, particularly as these involve sexual and reproductive health. The right to health is regarded as one of the most inviolable of all human rights. Academics and lawyers like Associate Professor Edwin Abuya and Dr Naomi Njuguna note that challenges facing women and girls with disabilities have been greatly exacerbated by the COVID-19 pandemic. In Kenya as in many parts of the world, women and children with disabilities are particularly susceptible to sexual abuse, neglect, and family violence. The authors underscore the injustice and unlawfulness of societal structures, attitudes, and policies that devalue women and girls with disabilities. They argue that equal treatment should extend to all aspects of sexual and reproductive health, including rights to birth control and family planning. Their essay makes interesting observations of how the situation facing women has been affected by both medical systems overwhelmed by COVID-19 patients and by measures introduced to control infections.

Cycles of Disaster

In 2022, the decision by Russia to invade the Ukraine generated new crises that saw very substantial refugee flows into Europe. Research by the contributors to this book – and that of UNHCR, OHCHR, and others – suggest that persons with disabilities are sure to be represented among those displaced by this new violence and armed conflict. This is particularly the case as so many of the fugitives are women and children, – a cohort with recognized vulnerabilities that make them more susceptible to harms that can result in disabilities (World Vision, 2022).

It is clear from the thoughtful chapters in this section that much work is still required to identify persons with disabilities in emergency and in conflict situations. Without appropriate methods of identification, especially of disabilities which are not readily apparent, it is difficult for countries and UN agencies to ensure that reasonable accommodations and assistance are appropriately provided.

It is also clear that there has been insufficient consultation with persons with disabilities and disabled persons organizations concerning risk identification and risk reductions in times of disasters. It is only through dialogue that the human rights and needs of persons with disabilities can be recognized in situations of disasters, national emergencies, and situations of armed conflict. Finally, it is essential to plan responses before the occurrences of disasters which are likely to increase throughout the remainder of this century.

Cross-References

- ▶ Disability and Disaster Risk Preparedness
- ▶ Disability and Refugee Protection
- ▶ Disaster and Climate Change-Induced Displacement of Persons with Disabilities: A Human Rights Perspective
- ▶ Inclusive Processes for Refugees with Disabilities: Improving Communication for Deaf Forced Migrants
- ▶ Widening the Scope of Non-refoulement? The CRPD and the Protection of Persons with Disabilities in Displacement
- ▶ Women and Girls with Disabilities in the Heart of the COVID-19 Crisis: Safeguarding Sex and Reproductive Health Rights

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Disaster and Climate Change-Induced Displacement of Persons with Disabilities: A Human Rights Perspective

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Walter Kälin

Contents

Abstract

Disasters and adverse effects of climate change may significantly exacerbate pre-existing vulnerabilities of persons with disabilities. This is particularly true if such persons are displaced within their country or across borders. The systematic promotion and mainstreaming of disability-inclusive and rights-based approaches to disaster risk management and climate action are crucial to mitigate these challenges. The human rights of persons with disabilities which remain applicable during disasters and the principles of non-discrimination and equality of opportunity, participation and inclusion, accessibility, and reasonable accommodation help in shaping disability-inclusive measures to prevent displacement as well as the provision of protection and assistance during displacement. Finally,

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including persons with disabilities in programs and projects on durable solutions and ensuring their participation in decisions aimed at ending their displacement are crucial to avoid replicating and rebuilding barriers and ensuring their full and effective participation in society.

Keywords

Climate change · Disability · Disaster · Displacement · Human rights

Introduction

Displacement Dynamics

Disasters triggered by flooding, tropical storms, droughts, and heat waves and other weather- and climate-related events or geophysical hazards such as earthquakes, volcano eruptions, or tsunamis have devastating impacts on very large numbers of people. Between 2010 and 2019, an average of 102 such events affected 201.3 million people and caused 61,707 deaths per year.[1] On average, they also trigger 24.5 million new displacements per year.[2] Many displaced persons can return to their homes after a few days or weeks, but others are caught up in protracted displacement. Most of them remain within their own country as internally displaced persons (IDPs). Some, however, are forced to seek refuge abroad.[3] Others may choose to migrate in anticipation of or in the aftermath of a disaster as a way to cope with risks and impacts of sudden- or slow-onset natural hazards and adverse effects of climate change. Finally, authorities or communities may decide to relocate people if actual or anticipated hazards would make it too risky or impossible for them to return to or remain in their homes. In 2010, the States Parties to the 1992 UN Framework Convention on Climate Change (UNFCCC) recognized forced displacement, voluntary migration, and planned relocation as part of the challenge to adapt to climate change.[4]

While it is difficult to predict numbers, it is clear that adverse effects of climate change such as sea level rise or desertification and other environmental degradations will incite or force millions of people to leave their homes in the future: The World Bank estimates that more than 143 million people will move within their countries in Latin America, sub-Saharan Africa, and South Asia by 2050 unless we take robust action to mitigate and adapt to climate change and invest in development aimed at reaching the Sustainable Development Goals.[5]

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[1] CRED (2021), p. 1

[2] IDMC (2021), p. 78

[3] See the examples described in The Nansen Initiative (2015), Vol. II, pp. 8–34.

[4] COP16 (2010), para. 14(f)

[5] Kumari Rigaud et al. (2018)

Displaced Persons with Disabilities: An Invisible Group

Persons with disabilities are numerous[6] among displaced people. However, they remain largely invisible.

While the lack of comprehensive and solid data and knowledge on people displaced in the context of disasters and adverse effects of climate change in general is recognized as a key challenge,[7] the situation is even worse when it comes to displaced persons with disabilities. Global numbers are not available as data disaggregated by disability are scarce.[8] This is at odds with CPRD, Article 31(1), requiring States to generate data needed for policies to respect, protect, and fulfil the human rights of such persons. Even where data exist, they are often problematic. The International Organization for Migration (IOM), for instance, reported in early 2021 that among the 844,642 persons internally displaced in Ethiopia's Somali region due to not only conflict but also drought and flooding or landslides, only 5315 individuals had mental or physical disabilities.[9] While persons with disabilities are estimated to represent around 15 percent of the world population (UNDP 2018: 56), this figure amount to less than 1 percent of this population. When volcanic activities displaced people in Vanuatu in 2017, only 37 persons among a total of 5125 IDPs were identified as persons with disabilities although up to 12 percent of the country's total population are estimated to belong to that category.[10] While higher casualties among those whose disability prevents them to evacuate or flee[11] may contribute to these differences, this factor alone cannot explain these discrepancies. Rather, as the Special Rapporteur on the human rights of internally displaced persons (hereafter: Special Rapporteur) highlighted, the "lack of accessibility, adequate capacity and/or prioritization, stigma and unduly narrow definitions of disability, particularly with regard to psychosocial functioning" are among the factors contributing "to under-identification of internally displaced persons with disabilities."[12]

Displaced persons with disabilities and their rights remain largely invisible in relevant international processes, too. The topic is rarely addressed by States in the context of the Universal Periodic Review.[13] With the exception of the Committee on the Rights of Persons with Disabilities, the same is true for UN treaty bodies. While they often include persons with disabilities when mentioning categories of people with special needs and vulnerabilities such as children or refugees and migrants, specific recommendations such as that of the Committee on Economic, Social and Cultural Rights to the Central African Republic to ensure "that displaced persons

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[6] Human Rights Council (2020), para. 14

[7] Nansen Initiative (2015), Vol. I, paras. 112 f

[8] IDMC (2021), p. 2

[9] IOM (2021), p. 16

[10] IDMC (2021), p. 2

[11] See Fujii (2012).

[12] Human Rights Council (2020), para. 46

[13] Human Rights Council (2020), para. 24

suffering from disability and living in camps are allowed to enjoy adequate protection and humanitarian assistance on equal terms, as well as access to their basic requirements, such as food, water and sanitation, health care and education"[14] remain very rare. Particularly noteworthy is the 2020 thematic report of the Special Rapporteur on the human rights of internally displaced persons, Cecilia Jimenez, on the rights of internally displaced persons with disabilities.[15]

Overview

As these examples indicate, displaced persons with disabilities are not sufficiently seen as individuals with specific needs and interests beyond those shared by other people displaced in disaster and climate change contexts. This chapter argues that taking the human rights of persons with disabilities seriously contributes significantly to preventing their displacement, addressing their assistance and protection needs during displacement, and finding solutions ending their displacement in ways that address these needs. It starts with a description of the role of human rights in disaster situations more generally (section "Human Rights in Disaster Contexts"). This is followed by suggesting a concept of displacement in the context of disasters and adverse effects of climate change which helps to identify entry points for human rights-based action (section "Conceptualizing Displacement in the Context of Disasters and Climate Change"). The chapter then discusses in more detail those human rights which are particularly relevant for preventing displacement, protecting and assisting displaced persons with disabilities, and finding durable solutions for them (section "Protecting Persons with Disabilities Throughout the Displacement Cycle"). The chapter concludes with a call to domestic, regional, and UN human rights mechanisms to play a more active role in safeguarding the human rights of persons with disabilities throughout the displacement cycle.

Human Rights in Disaster Contexts

Relevance

Disasters and adverse effects of climate change affect the human rights of persons with disabilities in many ways.[16] However, it is often assumed that human rights do not play a significant role in such situations because displaced people supposedly face few protection challenges compared to people forced to flee during conflict and who might be attacked, exploited, or otherwise harmed by a party to the conflict or criminal elements even when living in camps or irregular settlements. As a

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[14] Committee on Economic, Social and Cultural Rights (2018), para. 12(c)

[15] Human Rights Council (2020), paras. 13–102

[16] Office of the High Commissioner for Human Rights (2020)

consequence, humanitarian organizations providing assistance to survivors of a disaster may neglect protection risks. However, the right to protection of life; the rights to access to live-saving food and water, shelter, or medical services; the right to protection from sexual and gender-based violence; guarantees related to the reunification of separated families; rights related to the restitution of lost documentation; or housing, land, and property rights are highly relevant for not only disaster-displaced persons in general[17] but also displaced persons with disabilities.[18] More generally, disasters tend to exacerbate not only vulnerabilities but also pre-existing patterns of discrimination and marginalization. Unlike during armed conflict, protection problems in disaster contexts are, as I have highlighted elsewhere, often "the consequence of neglect, lack of capacity or inappropriate policies that do not take into account the human rights dimension of disasters" rather than the result of deliberate infliction of harm.[19] The Convention on the Rights of Persons with Disabilities (CRPD), Article 11, reflects these realities by obliging States Parties to take, in accordance with their human rights obligations, "all necessary measures to ensure the protection and safety" of persons with disabilities affected, inter alia, by disasters.

Another problematic assumption suggests that human rights play a limited role because they can be suspended during times of emergency. Article 4 of the International Covenant on Civil and Political Rights (ICCPR) and equivalent provisions in regional human rights conventions[20] on derogation permit the suspension of such rights if a "public emergency ... threatens the life of the nation." However, this possibility is of limited practical relevance[21]: Such measures are limited "to the extent strictly required by exigencies of the situation" in terms of duration, location, and the rights whose application is temporarily suspended. Furthermore, certain rights, including the right to protection of life, are non-derogable. While a State might, for instance, be unable to ensure guarantees such as bringing looters promptly before a judge during a disaster as required by ICCPR, Article 9(3), and therefore would be entitled to derogate from them, occasions where relevant rights of disaster-displaced persons with disabilities could be legitimately suspended are difficult to imagine. It is thus no coincidence that States seldom invoke derogation measures in disaster contexts and usually limit them to the freedom of movement, for instance, to keep looters out disaster areas, and the freedom of assembly.[22] While other human rights conventions, including the CRPD, do not contain derogation clauses, States may, in very exceptional and extreme situations, justify temporary disregard of

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[17] Human Rights Council (2009), para. 4

[18] Stein and Lord (2011), pp. 404–413; Human Rights Council (2020), paras. 56 f

[19] Kälin (2012), p. 125; Human Rights Council (2009), para. 5

[20] American Convention on Human Rights, Art. 27 (1969); European Convention for the Protection of Human Rights and Fundamental Freedoms, Art. 15

[21] Sommario (2018)

[22] Sommario (2018), 111–12

certain guarantees with reference to necessity as a ground precluding wrongfulness under international law,[23] but such cases hardly occur.

Obligations

A State's triple human right obligation to respect, protect, and fulfil[24] continues to apply in disaster and climate change situations, albeit with some peculiarities. The *duty to respect* may be absolute such as in the case of the prohibition of torture, but many rights can be limited for reasons such as the protection of public order and public health or, in the case of economic, social, and cultural rights,[25] for the promotion of the general welfare in a democratic society. Such reasons often carry great weight in disaster situations and may justify more severe limitations, for example, on the freedom of movement or property rights, than would be permissible at other times. Authorities may also feel compelled to oblige certain people to participate in rescue and recovery operations without pay. Such work does not violate the absolute prohibition of forced labor as, according to ICCPR, Article 8(3)(c), a "service exacted in cases of emergency or calamity threatening the life or well-being of the community" does not amount to such labor.

The *duty to protect* against threats emanating from private actors or natural and human-made hazards[26] is particularly relevant in disaster contexts. According to the European Court of Human Rights, this duty includes, among others, the obligation of competent authorities to adopt laws and implement measures to reduce and mitigate disaster risks; identify and monitor particularly hazardous locations and dangerous situations; inform people living there about possible risks; and ensure their evacuation in case of imminent hazards.[27] The duty to protect persons with disabilities is explicitly enshrined in CRPD, Article 11, with its reference to the obligation "to ensure the protection and safety of persons with disabilities in situations of risks," including disaster situations. Article 16(1) obliges States more generally to "take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities. . . from all forms of exploitation, violence and abuse . . .."

The duty to protect is not absolute but exists to the extent that authorities know or should know the threat and possess, to use the words of the European Court of Human Rights, the means which, "judged reasonably," would be suitable "to avoid that risk."[28] The actual level of due diligence required to provide protection depends

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[23] International Law Commission (2001), Article 25

[24] Kälin and Künzli (2019), 87–112

[25] International Covenant on Economic, Social, and Cultural Rights, Article 4

[26] Burson et al. (2018), 384–393

[27] Kälin and Künzli (2019), p. 98

[28] European Court of Human Rights (Grand Chamber) (1998), para. 116. See also Inter-American Court of Human Rights, (2012), para. 245.

not only on the specific situation but to some extent also on the right at risk. Thus, unlike in the case of the right to life, the duty to protect the right to property is, according to the Court, less stringent where property is lost not as a result of events occurring under the responsibility of the public authorities but destroyed by a natural hazard.[29] On the other hand, the obligation to protect is particularly strict where the rights of persons with specific vulnerabilities, including persons with disabilities,[30] are at risk.

The *duty to provide* requires States to provide the legal, institutional, and procedural measures and conditions necessary for rights holders to fully realize and enjoy their human rights. In certain situations, the duty also includes the obligation to provide goods such as food and shelter or basic services, including health and education. Thus, according to CRPD, Article 28(1), "States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing." CRPD, Articles 24 and 25, on the rights to education and to the enjoyment of the highest attainable standard of health obliges them to ensure access to and inclusion of such persons in educational and health services. These rights are particularly relevant for people with disabilities who need humanitarian assistance because they are displaced. However, in such situations, States may lack sufficient resources to provide what is necessary in a disaster situation. Nevertheless, as highlighted by the Committee on Economic, Cultural and Social Rights, every State has the "minimum core obligation to ensure the satisfaction of, at the very least, minimum essential levels" of the rights to food, shelter, health, and education. Thus, a State Party in which, for instance, "a significant number of individuals is deprived of essential foodstuffs, of essential primary health care, of basic housing, or the most basic forms of education is, prima facie, failing to discharge its obligations under the Covenant."[31] If the State does not possess the necessary means and resources to ensure this minimum, its authorities are obliged to call on the international community for support[32] and authorize humanitarian access for UN agencies and international non-governmental organizations ready to help.

In addition to these general duties, States must respect specific principles and rights enshrined in the CRPD when persons with disabilities risk displacement or are already displaced. Besides CRPD, Article 11, which is the topic of another chapter in this book,[33] certain general principles enshrined in CRPD, Article 3, are particularly relevant:

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[29] European Court of Human Rights, (2008), paras. 173–4

[30] European Court of Human Rights (2012), paras. 141–150

[31] Committee on Economic, Cultural and Social Rights (1990), para. 10

[32] International Covenant on Economic, Social and Cultural Rights, Article 2(1). Committee on Economic, Cultural and Social Rights (1990), para. 13. See Burson et al. (2018), pp. 402–407.

[33] See ▶ Chap. 88, "Widening the Scope of Non-refoulement? The CRPD and the Protection of Persons with Disabilities in Displacement."

The principles of *non-discrimination* and *equality of opportunity* enshrined in CRPD, Article 3(b) and (e), and the right to equality and non-discrimination guaranteed in Article 5 are important because multiple and intersectional discrimination is a real risk in displacement situations.[34] Displaced persons might not only be discriminated against on the basis of their disability, intersecting with other relevant grounds such as gender, age, ethnicity, or religion,[35] but also experience adverse distinctions due to the fact that they are displaced – a form of discrimination explicitly prohibited by the Guiding Principles on Internal Displacement.[36] The CRPD not only "seeks to combat direct discrimination by treating persons in a similar situation similarly" which helps "to combat negative stereotyping and prejudices" but, as highlighted by the Committee on the Rights of Persons with Disabilities, promotes substantive equality and thus "seeks to address structural and indirect discrimination," including by addressing power relations.[37] This model of "inclusive equality" recognizes and "reaffirm[s] the social nature of people as members of social groups and the full recognition of humanity through inclusion in society" and "make[s] space for difference as a matter of human dignity."[38] This is particularly important for persons with disabilities as being displaced too often means a life on the margins of society.

The principle of full and effective *participation and inclusion* in society and the equal rights of all persons with disabilities to live in the community with choices equal to others as enshrined in CRPD, Articles 3(c), and the right to participate in the conduct of public affairs guaranteed by Article 29(c) build on this understanding of equality and non-discrimination. It gives persons with disabilities voice and visibility and works against their segregation from other displaced persons and the communities hosting them. As the Special Rapporteur put it, "ensuring participation in all decision-making processes helps overcome protection, accessibility and communication barriers, and reduces discriminatory and exclusion impacts. Participation ensures good governance and social accountability and helps reduce stigma."[39]

The principle of *accessibility* and the rights to access information, education and health services, the labor market, and adequate food, clothing, and housing[40] are essential in all phases of the displacement cycle. Thus, the Committee on the Rights of Persons with Disabilities emphasizes that in situations of disaster, "the emergency services must be accessible to persons with disabilities, or their lives cannot be saved or their well-being protected"; furthermore, "[a]ccessibility must be incorporated as

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[34] Committee on the Rights of Persons with Disabilities (2018a), para. 19

[35] Human Rights Council (2020), para. 17

[36] Guiding Principles on Internal Displacement (1998), Principle 1(1), second sentence

[37] Committee on the Rights of Persons with Disabilities (2018a, b), para. 10

[38] Ibid., para. 11

[39] Human Rights Council (2020), para. 31

[40] CRPD, Articles 3(f), 9, 21, 24, 25, 27, and 28

a priority in post-disaster reconstruction efforts," and "disaster risk reduction must be accessible and disability-inclusive."[41]

Finally, the principle of *reasonable accommodation* calls for modifications and adjustments of measures to prevent displacement, provide assistance and protection during displacement, and achieve durable solutions ending displacement to the extent that they are necessary "to ensure that persons with disabilities" can enjoy their human rights "on an equal basis with others" and do not impose "a disproportionate or undue burden" on the duty bearers (CRPD, Article 2). While, depending on the circumstances, space for accommodations might be limited in the immediate emergency phase of a sudden-onset disaster, adjustments are certainly possible when preventive measures are implemented, displacement becomes protracted, or efforts to find durable solutions are under way.

Conceptualizing Displacement in the Context of Disasters and Climate Change

A deeper understanding of what disasters are and when displacement occurs in such contexts is essential to comprehend how the human rights of persons with disabilities can contribute to preventing their displacement, addressing their protection and assistance needs during displacement, and finding solutions ending their displacement.

The UN defines disasters as situations where the interaction of a hazardous event "with conditions of exposure, vulnerability and capacity" causes losses and negative impacts that lead to a "serious disruption of the functioning of a community or a society."[42] Disasters, thus, are not "natural" but occur when people are exposed to a natural hazard and lack the capacity or are otherwise too vulnerable to cope with its impacts. This definition covers sudden-onset events as well as slow-onset processes such as drought, desertification, or sea level rise, provided they overwhelm the coping capacities of affected societies and communities. It also implies that the prevalent dichotomy of sudden- and slow-onset disasters is problematic. In fact, it is often the interaction between the two that disrupts the functioning of a community or society. Low-lying atoll islands become uninhabitable where sea level rise not only causes coastal erosion but also contributes to stronger and higher storm tides causing the salinization of ground water and previously fertile soil.[43] Biological hazards triggering epidemics and pandemics such as COVID-19 can, as explicitly recognized by the Sendai Framework for Disaster Risk Reduction (hereafter Sendai Framework),[44] also trigger disasters when societies are unable to manage the medical as well as the social and economic impacts of pathogens.

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[41] Committee on the Rights of Persons with Disabilities (2014), para. 36

[42] UNDRR, Definitions

[43] International Law Association (2016), p. 21

[44] Sendai Framework (2015), para. 15

Building on the UN's notion of disaster, the Nansen Initiative Protection Agenda, the outcome of a state-led process of consultations endorsed in 2015 by 109 States, understands disaster displacement as "situations where people are forced to leave their homes or places of habitual residence as a result of a disaster or in order to avoid the impact of an immediate and foreseeable natural hazard" and highlights that "[s]uch displacement results from the fact that affected persons are (i) exposed to (ii) a natural hazard in a situation where (iii) they are too vulnerable and lack the resilience to withstand the impacts of that hazard."[45]

The element of vulnerability highlights the multi-causality of displacement. People exposed to hazards and environmental degradation may lack resilience for a multitude of socioeconomic and political reasons, including poverty, social and economic marginalization, poor urban planning, expansion of settlements into risk-prone areas, population growth, weak governance regarding disaster risk reduction and management, and violence or armed conflict. As compared to the impacts of the natural hazard itself, these human factors contribute as much as, and sometimes even more, to whether affected people will be able to stay or forced to move. An illustrative example is the case of the Somali pastoralists displaced internally as well as to neighboring countries in 2011/2012 when drought-induced food insecurity turned into famine due to human factors such as weak clan protection, the lack of food assistance reaching them, and the ongoing armed conflict.[46]

Understanding disaster- and climate change-related displacement as a consequence of the interaction of hazards with exposure and vulnerability offers the advantage of providing three entry points for action addressing displacement risks. First, hazards linked to climate change can be mitigated by reducing the emission of greenhouse gases and enhancing sinks and reservoirs for them, in particular forests, in accordance with the goal of the 2015 Paris Agreement to keep global warming well below 2 °C above pre-industrial levels.[47] Second, reducing vulnerability and strengthening resilience through measures related to disaster risk reduction and climate change adaptation, and more generally development in line with the Sustainable Development Goals,[48] can significantly help people to stay. Finally, exposure to hazards can be reduced by helping people to move out of harm's way before disasters strike with measures such as anticipatory evacuation, planned relocation, and provision of pathways for safe, orderly, and regular migration.[49] However, as such measures will often not be sufficient to prevent displacement, protecting and assisting persons displaced within their country or across borders and helping them finding durable solutions ending their displacement remain highly relevant in most disaster contexts.

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[45] Nansen Initiative (2015) Vol. I, para. 16

[46] Scott (2020), pp. 145–48

[47] Paris Agreement, Articles 2, 4, 5

[48] UN General Assembly (2015), para. 59

[49] Nansen Initiative (2015) Vol. I, paras. 76–98, 116–122

Protecting Persons with Disabilities Throughout the Displacement Cycle

Helping Persons with Disabilities to Stay

Efforts aimed at preventing displacement have clear human rights implications. In the Budayeva case, the European Court of Human Rights found a violation of the right to life when people were killed during a particularly strong mudslide because authorities had, among others, failed to repair a mud retention dam and collector protecting the town of Tyrnauz from such seasonal hazards.[50] According to the Court, competent authorities have a positive obligation to implement disaster risk reduction measures in hazardous areas where residents are exposed to potentially mortal risks.[51] More generally, the Sendai Framework calls on States to develop national and local disaster risk reduction strategies and to substantially increase their number by 2020.[52] Integrating displacement risks in such strategies by identifying high-risk areas and their populations, including groups likely to face higher levels of risks such as poor people living in informal settlements, and developing targeted programs to build their resilience[53] are important measures that help people stay in case of a disaster. The Sendai Framework highlights the importance of "comprehensive public and community consultations" during the development of such strategies.[54] However, according to a UN survey conducted in 2013, persons with disabilities are rarely included in such consultations and unable to participate in community-based disaster management and risk reduction processes.[55] Without participation and inclusion[56] as required by CRPD, Articles 3(c) and 29(b), relevant barriers and specific accommodations needed to overcome them may not be identified and thus remain unaddressed. The Committee on the Rights of Persons with Disabilities has repeatedly called on States to adopt and enact disability-inclusive disaster risk reduction strategies[57] and criticized the "lack of policies regarding consultation of organizations of persons with disabilities in planning, implementing, monitoring, and evaluating disaster risk reduction strategies."[58]

Similar considerations apply to efforts to adapt to climate change,[59] including the development of national and local climate change adaptation plans under the

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[50] European Court of Human Rights (1998), paras. 18 ff, 147 ff

[51] Ibid., para. 156

[52] Sendai Framework (2015), paras. 18(e) and 27(b)

[53] UNDRR (2019), p. 29 and 49

[54] Sendai Framework (2015), para. 27(f)

[55] UNISDR (2013), p. 2

[56] Twigg et al. (2018). See also ▶ Chap. 86, "Disability and Disaster Risk Preparedness."

[57] For example, Committee on the Rights of Persons with Disabilities (2019a), para. 22(b) and (2018b), para. 23(b)

[58] Committee on the Rights of Persons with Disabilities (2019b), paras. 24(a) and 25(a)

[59] Bell et al. (2020)

UNFCCC. In 2018, the Conference of Parties supported a recommendation to "integrate climate change related human mobility challenges and opportunities into national planning processes"[60] and encouraged States Parties "to apply a participatory approach to adaptation planning and implementation" by seeking "stakeholder input, including from persons with disabilities . . .."[61]

Helping Persons with Disabilities to Move out of Harm's Way

Helping people to move out of harm's way before disasters strike is not only an effective way to protect people but may also be required by international human rights law.[62] Such measures include anticipatory evacuation followed by return shortly after the hazard, planned relocation of whole communities, and the facilitation of internal or cross-border migration.

Evacuations,[63] understood as "the rapid movement of persons away from the immediate threat or impact of a disaster to a place of shelter, in order to ensure their security, safety, and well-being,"[64] can be voluntary or, where unavoidable or ordered by authorities, forced. Orders to evacuate may be required by the human rights duty to protect life if despite a life-threatening risk people do not voluntarily evacuate,[65] but such orders must be provided for by law and necessary to protect the life and health of affected persons because less intrusive measures would be insufficient.[66] In both cases, competent authorities have the duty to "provide support to those unable to evacuate themselves."[67] Thus, evacuation plans must, for instance, provide for warning systems designed to reach people with visual and hearing impairments as well as address the timely and safe evacuation of people with limited mobility.[68]

Planned relocation of whole communities, villages, or even towns and cities is a measure of last resort where sea level rise renders coastal areas or low-lying atoll islands uninhabitable. Relocating people may also become unavoidable where, as in the case of landslides or volcano eruptions, areas of return have become permanently uninhabitable or too dangerous for human habitation. Finally, planned relocation is often undertaken as a measure of disaster risk reduction. Most relocations take place within countries. Fiji, for instance, is already undertaking relocations of villages away from eroding coastlines and adopted specific Guidelines on climate

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[60] COP24 (2018), Decision 10/CP.24, Annex, para. 1(g)(iv)

[61] COP24 (2018), Decision 9/CP.24, para. 8

[62] Burson et al. (2018). See also International Law Association (2018), Principles 5–7.

[63] Burson et al. (2018), pp. 393–398

[64] International Law Association (2018), Definitions

[65] European Court of Human Rights (1998), paras. 148 ff

[66] International Law Association (2018), Principle 5(2)

[67] International Law Association (2018), Principle 5

[68] UNDRR (2019), p. 46; Committee on the Rights of Persons with Disabilities (2018a) para. 23(c)

change-related relocation in 2019.[69] A recent desk study identified over 300 cases of disaster- and climate change-related relocations.[70] Planned relocations to other countries are even more challenging. While no contemporary examples exist, they occurred in the past, for instance, during colonial times in the South Pacific,[71] and could become a reality in the future for citizens of low-lying Small Island Developing States (SIDS).

Planned relocations[72] are problematic in human rights terms,[73] particularly where they affect communities with special cultural, religious, or economic attachments to their lands or where the new sites are not suitable and relocated people end up in poverty and marginalization.[74] The International Law Association's Sydney Declaration of Principles on the Protection of Persons Displaced in the Context of Sea Level Rise (hereafter Sydney Declaration) therefore highlights the need for the full, free, and informed consent of affected persons and communities and clarifies that where such consent cannot be obtained, relocation is only permissible "as a measure of last resort to safeguard the lives and safety of those affected," provided it is based on national law and carried out "in accordance with relevant international legal standards." Furthermore, "[p]ersons affected by a planned relocation, including those who receive relocated persons, must be informed, consulted, allowed, and enabled to participate in all relevant decision-making processes."[75] These principles fully apply to persons with disabilities as they must have access to relevant information, be consulted, and allowed to participate as a matter of law (CRPD, Article 3, 21, and 29). Furthermore, and depending on the circumstances, full respect for CRPD, Articles 3(f) and 9, may provide unique opportunities to plan relocation sites in ways that do not replicate physical barriers which existed at the original site and enhance overall accessibility.

Internal or cross-border migration is an important coping mechanism for people who anticipate adverse impacts of climate change and decide to move when they still have some choice when and where to go. The liberty of movement, including the right of persons with disabilities to exercise it "on an equal basis with others" (CRPD, Article 18), is relevant for internal migration. While this provision also entitles them to leave their own country, a concomitant general right to be admitted to another State does not exist. However, as shown below (section "Protecting Displaced Persons with Disabilities"), affected persons may be entitled under bilateral or regional agreement on the free movement of persons. Beyond this, much can be done by States. Important steps recommended by the Sydney Declaration include recognizing "temporary, circular, or permanent migration across borders" as an

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[69] Government of Fiji (2019)

[70] Bower and Weerasinghe (2021)

[71] McAdam (2014)

[72] Burson et al. (2018), pp. 398–401

[73] McAdam and Ferris (2015)

[74] African Commission on Human and Peoples Rights (2010)

[75] International Law Association (2018), Principle 6. See Burson et al. (2018), pp. 398–401.

important way "to adapt to climate change," reviewing existing laws and agreements and considering "consider[ing] new laws and agreements, to facilitate migration as an adaptation measure."[76] Where this is done, such instruments and laws must cover persons with disabilities in accordance with the principles of inclusion, equality of opportunity, and accessibility (CRPD, Article 3).

Protecting Displaced Persons with Disabilities

Measures to mitigate displacement risks are not always sufficient to avoid displacement. Those who seek refuge *within their own country* become internally displaced persons (IDPs), that is, "persons or groups of persons who have been forced or obliged to flee or to leave their homes or places of habitual residence, in particular as a result of or in order to avoid the effects of [. . .] natural or human-made disasters," provided they "have not crossed an internationally recognized state border."[77] As IDPs, they are entitled to protection and assistance in accordance with the 1998 UN Guiding Principles on Internal Displacement, a soft law instrument based on and reflecting binding international law. Although legally non-binding, they are universally recognized as "important international framework for the protection of internally displaced persons"[78] and have been incorporated in a series of domestic laws and policies.[79] The Guiding Principles mention disability as a prohibited ground for discrimination (Principle 4) and state unequivocally that IDPs "with disabilities shall receive to the fullest extent practicable and with the least possible delay, the medical care and attention they require," as well as "access to psychological and social services" (Principle 19). Overall, they provide detailed guidance for the interpretation and application of CRPD, Article 11, on the obligation of States to take "all necessary measures to ensure the protection and safety of persons with disabilities."[80] This is important as such persons, while in displacement, often face particular barriers in accessing adequate shelter and housing, health, and educational services.[81] The COVID-19 pandemic has triggered additional risks and barriers for such persons living in IDP camps and settlements.[82]

For people *displaced across borders*, the key challenge is admission to the country of refuge and protection from forcible return.[83] Although often called

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[76] International Law Association (2018), Principle 7

[77] Guiding Principles (1998), Introduction, para. 2 (emphasis added)

[78] UN General Assembly (2005), para. 132 and many subsequent resolutions

[79] Orchard (2019), pp. 135–167

[80] Office of the High Commissioner for Human Rights (2015). See ▶ Chap. 88, "Widening the Scope of Non-refoulement? The CRPD and the Protection of Persons with Disabilities in Displacement."

[81] See the examples in IDMC (2021), pp. 3 f.

[82] Handicap International (2020)

[83] See ▶ Chap. 88, "Widening the Scope of Non-refoulement? The CRPD and the Protection of Persons with Disabilities in Displacement," by Stephanie Motz.

"climate refugees," they can only be considered refugees in the sense of the 1951 Convention relating to the Status of Refugees in a relatively small number of cases. However, the Convention provides protection if people are fleeing some form of persecution,[84] for instance, if activists are sanctioned for criticizing the authorities for their mismanagement of disaster relief efforts; if they are excluded from humanitarian assistance because they belong to a religious or ethnic minority; or if they are members of communities targeted by armed actors in situations where disasters and armed conflicts interact.[85] In practical terms, however, regional and domestic migration law is often more relevant than refugee law. In Africa, for instance, some sub-regional agreements on the free movement of persons make it possible for victims of drought or flooding to move across borders and find admission and economic opportunities in neighboring countries.[86] A recently adopted Protocol by the Intergovernmental Authority on Development (IGAD) contains a provision explicitly covering persons affected by disasters in the Horn of Africa.[87] In Central and South America, many countries use domestic provisions on humanitarian visa and temporary protection to admit disaster-displaced persons and have started harmonizing their migration laws.[88] At the global level, the 2018 Global Compact on Migration suggests to States to temporarily admit persons displaced by sudden-onset disasters "while adaptation in or return to their country of origin is not possible" and consider permanent relocation and immigration visa in cases where such adaptation or return remains impossible due to permanent effects of slow-onset events such as sea level rise or desertification.[89] The principle of inclusion (CRPD, Article 3) requires that displaced persons with disabilities are not excluded from such possibilities to be admitted to countries of refuge.

The weakness of existing practices and tools is their discretionary nature and the lack of predictability. However, emerging jurisprudence explores the potential of human rights instruments to provide stronger protection.[90] In the case of a citizen of Kiribati who claimed that return to his country of origin would violate his right to life, the UN Human Rights Committee, the expert body monitoring the implementation of ICCPR, decided "that without robust national and international efforts, the effects of climate change in receiving states may expose individuals to a violation of their rights" to life and the prohibition of inhuman treatment and in such cases trigger the non-refoulement obligations of the State deporting an individual to a country

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[84] UNHCR (2020)

[85] Scott (2020), pp. 32–87. See also McAdam (2012), pp. 39–51.

[86] Francis (2020/21), Wood (2019)

[87] IGAD (2021), Article 16

[88] Cantor (2021)

[89] UN General Assembly (2018), para. 21(g) and (h). Kälin (2018)

[90] See ▶ Chap. 88, "Widening the Scope of Non-refoulement? The CRPD and the Protection of Persons with Disabilities in Displacement," by Stephanie Motz for a detailed discussion.

seriously affected by climate change.[91] The European Court of Human Rights recognizes that deporting a vulnerable individual to a country where he or she would be exposed to serious suffering due to a lack of access to humanitarian assistance or medical treatment may amount to inhuman treatment.[92] While these judgements do not deal with disasters, their findings can be made fruitful for such situations, too.

Finding Durable Solutions

Ending displacement is often equated with return of people to their former homes or settlement in a new location. This understanding is too narrow as shattered lives cannot be rebuilt by simply moving to a specific location. In reality, ending displacement requires, inter alia, the reestablishment of physical safety; the restoration of housing; access to services and livelihoods; the restitution of property left behind; as well as the replacement of lost or destroyed personal documentation.[93] This is an often long and complex process which may be even more difficult for persons with disabilities. While, as the Special Rapporteur put it, they have the same rights as everyone "to make an informed and voluntary choice on what durable solution to pursue, they may not have access to information about the options and risks. Their right to participate in the planning and management of durable solutions may also be challenged by barriers to participation . . . Moreover, displaced persons with disabilities often have limited access to the resources they need to reach solutions . . ...."[94]

This highlights the need to systematically include persons with disabilities in programs and projects on durable solutions to avoid replicating and rebuilding barriers.[95] Efforts to achieve durable solutions provide unique opportunities to "build back better" not only in general but also for persons with disabilities, in particular by enhancing their access to an independent life and participation in all aspects of life (CRPD, Articles 9 and 19). Such mainstreaming is rarely done in national strategies on solutions beyond mentioning persons with disabilities as one of the several categories of people with specific needs and vulnerabilities. A noteworthy exception is Sri Lanka's durable solutions strategy which highlights the obligation to pay "specific attention . . . to provide the needed structural modifications, assistive/mobility devices, specialised care and/or training or personnel, and other measures to ensure that persons with disabilities are able to access assistance and fully enjoy their rights."[96]

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[91] Human Rights Committee (2020), para. 9.11. Article 6 of the Covenant guarantees the right to life, while Article 7 prohibits cruel, inhuman, and degrading treatment.

[92] See European Court of Human Rights (Grand Chamber), (2011) and (2016).

[93] IASC (2009)

[94] Human Rights Council (2020), para. 80

[95] Committee on the Rights of Persons with Disabilities (2017), para. 79

[96] Government of Sri Lanka (2016), sec. IV.6.3

Conclusion

Persons with disabilities are often particularly affected by disasters and adverse effects of climate change, and such events often exacerbate their pre-existing marginalization and vulnerabilities. They often lack voice, are rarely consulted, and cannot participate in decisions and activities aimed at mitigating displacement risks. During displacement, their "concerns or suggestions. . . appear rarely to reach humanitarian actors and coordination mechanisms or are disregarded"[97] and therefore remain unaddressed. Efforts supporting the displaced to achieve durable solutions may miss the chance to remove barriers and enhance the inclusion of persons with disabilities.

Rather than intentional, such neglect is often a consequence of weak or lacking mandates and responsibilities of authorities and international actors. Systematically promoting and mainstreaming disability-inclusive and rights-based approaches[98] to disaster risk management and climate action would help to remedy this situation. To achieve this, domestic courts and national human rights institutions, including national monitoring mechanisms in accordance with CRPD, Article 33, as well as UN treaty bodies and regional human rights courts and mechanisms will have to play a more active role. After all, human rights demand that persons with disabilities at risk of or being displaced in the context of disasters and adverse effects of climate change are explicitly recognized as rights holders who can and should call and hold duty-bearers to account.

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[97] Human Rights Council (2020), para. 33

[98] Human Rights Council (2016), paras. 4–6

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The Flow of a Treaty Practice: Article 11 of the Convention on the Rights of Persons with Disabilities and Disasters

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Janet E. Lord

Contents

Abstract

This chapter addresses the philosophical and practical implications of the treaty practice generated by Article 11 of the Convention on the Rights of Persons with Disabilities (CRPD) and its creative potential for disability rights protection, specifically in the context of natural disaster. It focuses on the activation of Article 11 of the CRPD through international and domestic legal commitments and institutional reforms and argues that a creative treaty practice is exerting

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potentially change-making progress in addressing the needs of persons with disabilities affected and displaced by disasters.

Keywords

Article 11 · Disability · Disaster · CRPD · Situations of risk · Humanitarian protection

Introduction

Disaster and Disability: The Context

Poverty disproportionately affects the population of approximately 1 billion persons with disabilities according to the *World Report on Disability* (World Health Organization & World Bank, 2011). Further, the latest data shows that the population of persons with disabilities is expected to double to 2 billion by 2050 (World Health Organization, Sensory Functions, n.d.). Persons with disabilities who live in a disaster-prone environment are more likely than not exposed to an elevated risk of harm for several reasons. First, risk for persons with disabilities is elevated on account of the intersectional relationship between disability and poverty, as the vast majority of persons with disabilities live in poverty (World Bank Group & Global Facility for Disaster Reduction and Recovery, 2020). Second, when disasters occur, persons with disabilities often face severe risks that threatens their immediate and long-term well-being (Office of the High Commissioner for Human Rights, 2015; Office of the High Commissioner for Human Rights, 2020). As noted by the report of the Office of the High Commissioner for Human Rights,

> persons with disabilities are often among those most adversely affected in an emergency, sustaining disproportionately higher rates of morbidity and mortality, and are among those least able to access emergency support. Sudden-onset natural disasters and slow-onset events can seriously affect the access of persons with disabilities to food and nutrition, safe drinking water and sanitation, health-care services and medicines, education and training, adequate housing and access to decent work.

Assessing and responding to risk means also considering intersectionality and the multidimensional discrimination that results from differentiated disability experience and the heterogeneity of disability. Thus, for example, as disasters tend to discriminate along gender and generational lines, women, children with disabilities, and older persons with disabilities may experience heightened risk. This assertion is borne out by research disclosing the disproportionate exposure to risk impacting risk and recovering for women and children during disaster (Vidili, 2018).

The Convention on the Rights of Persons with Disabilities (CRPD) addresses risk to individuals with disabilities in the context of disasters – and other emergencies – and its treaty practice has generated an impressive flow of concepts, commitments, guidance, and action in the domain of disability-inclusive disaster risk reduction and response (Convention on the Rights of Persons with Disabilities, 2006). Responses to the risks posed by disasters to persons with disabilities (and other marginalized groups) are occurring at multiple levels, in multiple forums, and involve a multitude of actors. This complex landscape of disability-inclusive disaster cooperation at the international level includes a wide range of treaty practice. Thus, action taken under the CRPD and other treaty regimes and international bodies, policy guidance and political signals provided by multilateral organizations, and informal cooperation among state and nonstate actors at various levels to advance disability-inclusive disaster action and response should all be considered part of this dynamic treaty practice. Cooperation across the full landscape of human rights treaties, institutions, and actors all play important roles in bolstering, complementing, and implementing Article 11 of the CPRD.

While the foregoing dynamics could perhaps be characterized as yet more evidence of fragmentation of international law, there are other ways to explain such phenomena (Koskenniemi, 2006). This chapter seeks to this chapter to tease out the intersecting flows that exist *across* international law where persons with disabilities are affected. In so doing, international disability rights and disaster law may be characterized as an exemplar of the transversality and coherence of international law. The position taken here is that international disability rights law in disaster as it is emerging functions as a laboratory for the dynamic development of international law more generally.

Part 1 of this chapter introduces the broad context for thinking about disability and introduces the concept of treaty practice used to assess developments in Article 11. Part 2 analyzes the signal contribution of the CRPD to disaster risk reduction and response in human rights law, not only through Article 11 but through a transversal reading of the CRPD in the specific context of disaster risk reduction. Part 3 contextualizes developments arising out of this area of treaty practice with a focus on how both the institutional arrangements of the CRPD have served to elevate Article 11 and disability-inclusive disaster risk reduction. It examines how international cooperation, including the practice of the World Bank, is elevating Article 11 concerns in the design and implementation of disaster risk management projects on the ground. Part 4 considers the implications of the proposal for an international convention on disasters in the light of Article 11 and the chapter concludes by examining the way forward and suggesting additional avenues for a treaty practice advancing disability-inclusive disaster risk management that are not fully realized.

Action, Process, and Flows: Framing a Treaty Practice for Disability-Inclusive Disaster Risk Reduction and Response

A human rights treaty – like any treaty but perhaps particularly so for an international instrument devoted to the protection of human flourishing – ought not to be understood as possessing a fixed, bounded, or closed identity (Wang, 2019). It has no "end" or definitive intention. And yet international lawyers looking at treaties and treaty practice have often struggled to capture the dynamism of treaty practice, too often working within the narrow defensive posture that seeks primarily to prove that a treaty (or other source of international law) is law and less on the complexity of processes by which treaties bring about change.[1] Others have worked more recently to signal the dynamism of treaties, calling attention to how treaties are "living regimes" or "interactional" or "expressive" in how they unfold (Wang, 2019, p. 850). This latter approach begins to capture human rights treaty practice as it unfolds, as it produces flows of concepts, ideas, and rules. These accounts are processual in their focus and thus better positioned to explain and account for the dynamic action that the CRPD, through Article 11 and its intersecting and traversal provisions, has brought about in the area of disability-inclusive disaster risk reduction and response. A further application of this notion is reflected in the work of the French philosopher, Gilles Deleuze, who conceptualizes social and political change in terms of flows; he speaks variously of flows of ideas, from person to person, or organization to organization (Deleuze, 2001). These approaches can help recognize the complexity of treaty practice – well beyond the relations between States inter se – and interrogate the creative, dynamic, and evolutionary flows of practice that result from a conceptualization of treaty practice as encompassing the work a treaty does among a wide range of actors.

The foregoing ideas help work through and make sense of the way a treaty moves ideas, brings about change in law, and impacts legal structures and institutional arrangements (Deleuze & Guttari, 1996; Deleuze, 2001). Under this notion, a treaty is its practice – lawmaking and implementation are no more than the connectivity they bring about – the connections they make, through structures, processes, States, people, and organizations. This is a world of difference, a world that is constantly in motion that cannot be captured through static accounts of treaty ratification, legislative reforms adopted or treaty body pronouncements issued at a particular point in time.

In sum, treaty practice, in its complexity, is best conceptualized as different flows of rights, actors, and institutions forging connections and creating networks in dynamic and sometimes chaotic ways. The flow of human rights treaty ideas seeps out in all directions: It is people, groups, treaties, ideas, principles, processes, institutions, partnerships, letters, lobbying, and other flowing parts. The project here is to apply this concept of treaty practice to the examination of Article 11 of the CRPD and its dynamic unfolding in the context of protection and disaster risk response.

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[1] The approach, embraced by scholars working to develop a research agenda for International Legal Process, was a response to this tendency and posits a processual account of international public law. See, e.g., O'Connell (1999).

Disaster, Risk, and Article 11

Article 11 and Risk in Protection in Risk Situations

One of the key provisions that sets out to launch a dynamic and flowing treaty practice – one that is to be read and applied transversally across the CPRD text and, more interestingly, across different domains of international law – is Article 11 of the Convention. That provision reads:

> States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters (CRPD, 2006).

The text of the CRPD thus recognizes that the rights of persons with disabilities are particularly at risk in situations of emergency – including but not limited to natural disasters. The treaty provides a framework to guide preparedness, response, and recovery efforts in disasters and climate events, as well as conflict situations and other humanitarian emergencies.

The documentation of grossly inadequate attention to the needs of persons with disabilities in disasters led to the adoption of Article 11 during the CRPD negotiations (Office of the High Commissioner on Human Rights, 2015). Its inclusion was by no means assured and indeed the explicit inclusion of disaster risk in Article 11 was a late addition, and not one originally included in initial drafts of the CRPD (Bantekas et al., 2019). The experience of Hurricanes Rita and Katrina, together with the Asian Tsunami, convinced drafters of the need for explicit mention of disaster as a situation of risk for persons with disabilities (Stein & Lord, 2011).

Article 11 adopts a risk reduction approach to protection and it reinforces States' obligations to ensure the protection and safety of persons with disabilities in situations of risk. A transversal reading of the CRPD is anticipated by the terms of Article 11 itself. There, the text acknowledges the protection obligations instantiated in other domains of international law, calling attention in particular to "international humanitarian law and international human rights law" in a non-exhaustive list (CRPD, 2006, art. 11). Brought within the ambit of the CRPD here, then, are those rules of international law that specifically obligate States to accord specific measures of protection to persons with disabilities, for instance, in various provisions of the Geneva Conventions, the Mine Ban, and Cluster Munitions Convention among others (Fourth Geneva Convention, 1949; Convention on the Prohibition of the Use, Stockpiling, Production, and Transfer of Anti-Personnel Mines and on their Destruction, 1999, Art. 6(3); Convention on Cluster Munitions, 2010).

Applying the CRPD Framework to Natural Disaster

Transversality as applied to the CRPD likewise requires reading across the provisions of the CRPD itself, here picking up on the notion that a reading of a human rights treaty is a dynamic and mutually reinforcing exercise. To illustrate, taking Article 3 of the CRPD as an example, its eight general principles help inform the obligation to protect persons with disabilities during situations of risk. Picking up on the general principle in Article 3 of autonomy and independence as well as inclusion means that inclusive approaches to disaster planning must be applied. Conversely, approaches that lead to segregation and separation, as in separate sheltering or evacuation sites for persons with disabilities during a disaster, would not align with the CRPD.

The CRPD Article 4(3), on the participation of persons with disabilities, requires that persons with disabilities benefit from and participate in disaster relief, emergency response, and disaster risk reduction strategies. This means, among other things, ensuring that the voices of persons with disabilities are heard in the overlapping phases of disaster prevention, preparedness, response, and recovery. To assist persons with disabilities through these situations and to ensure their voice is heard, it is critical to have their engagement early and throughout situations of disaster and disaster response as they are a tremendous resource in responding to situations of disaster and play critical roles in informing disaster response interventions that affect them and their communities.

Likewise, amplifying the voice of persons with disabilities means being heard in other CRPD domains, such as adjusting social protection to cushion the impacts of natural disasters (Article 28, Adequate Standard of Living and Social Protection) and on planning for an inclusive labor market and minimizing loss (Article 27, Employment). Article 28 also calls to attention to necessity of ensuring that persons with disabilities have access to food and water, a major problem in the context of emergencies for persons with disabilities and groups at risk. Article 29 (Participation in Political and Public Life) builds on participation and inclusion gives persons with disabilities voice and visibility and serves to undercut the prevailing paradigm of segregation and exclusion, including in disaster contexts.

The CRPD recognizes that situations of risk, including natural disasters, require specific measures that take into account the specific requirements of individuals with disabilities. This is anticipated, for instance, in the concept of reasonable accommodation (Articles 5 & 2) which requires individualized modifications and adjustments – in respect of preventive measures, disaster response including during displacement, and in efforts to develop durable solutions. Reasonable accommodation and other supports measures are applicable, therefore, across the domains of forced migration, mobility, access to basic services like food and water, health, education, and employment opportunities.

While reasonable accommodation addresses specific, individualized measures that an induvial with a disability may require, the CRPD principle of accessibility addresses the collective – and strongly urges anticipatory measures to facilitate access, whether to CRPD rights of access to information, education, and health services, the labor market, and adequate food, clothing, and housing, all of which are essential in relation to disasters and their impacts, to persons with disabilities (Convention on the Rights of Persons with Disabilities, 2006, art. 3(f), 9, 21, 24, 25, 27, and 28). Article 9 (Accessibility) requires States Parties to ensure that people can access, on an equal basis with others, the physical environment, transportation services, information and communications technologies and systems, and all public facilities and services which include emergency services and facilities. Article 9 makes explicit the link to emergency services in specifically mandating measures to make "information, communications and other services, including. . .emergency services accessible." The CRPD Committee has underscored this point emphasizing that in situations of disaster "the emergency services must be accessible to persons with disabilities, or their lives cannot be saved or their well-being protected"; furthermore, "[a]ccessibility must be incorporated as a priority in post-disaster reconstruction efforts," and "disaster risk reduction must be accessible and disability-inclusive" (Committee on the Rights of Persons with Disabilities, 2014, p. 36).

Provisions in the CRPD likewise give recognition to the fact that the adverse impacts of risk situations on individuals with multiple vulnerability factors, including women and girls with disabilities (Articles 6 & 7), necessitate the participation of persons with disabilities in disaster response planning for emergency situations and evacuations, as well as humanitarian emergency response and health care services.

Especially important in addressing the risks that disasters pose to persons with disabilities are those provisions in the CRPD that are designed to dismantle systems of segregation and reflected in Article 3's principles of inclusion, autonomy, and independence. Disaster situations pose a serious problem for the CRPD goal of inclusion. First, persons with disabilities who are in segregated and congregate living arrangements such as nursing homes and orphanages are seriously at risk when disaster strikes absent careful planning for evacuation and other supports. Second, recovery and rebuilding in the wake of a disaster while offering new paths can nonetheless reinforce segregation when noncommunity-based options are rebuilt, renovated, or even built anew. In this respect, disability-inclusive disaster responses must be carried out in line with CRPD principles of inclusion and independence (Article 3) and in relation to Article 19 of the CRPD which obligates States to advance living independently and in the community and to respect the right to persons with disabilities to decide where and with whom they live. The risk is that when disasters strike and donors arrive, there is a serious danger of replicating segregated responses in the aftermath of disaster, if not by publicly funded initiatives, then by privately funded ones that are prevalent in disaster recovery zones.

Finally, in line with Article 31 (Disability Data and Statistics) of the CRPD, an essential aspect of disability-inclusive protection is ensuring the collection of baseline data on barriers and accessibility measures to understand and assess disability inclusion in recovery and reconstruction. Also required are measures to ensure that post-disaster assessments are inclusive of persons with disabilities and their needs. New policies on disability in this context should align with the CRPD's standards on data collection to guide disability-inclusive recovery and reconstruction.

The foregoing suggests a transversal reading of the CRPD to animate full the promise of Article 11 on protecting persons with disabilities throughout the disaster risk management cycle. And, of course, accessible disaster risk management benefits a wide range of groups, whether accessible mass transit enabling evacuation or the creation of accessible early warning systems that warn people in multiple information formats of impending danger. What follows is an analysis of some of the treaty practice emerging from Article 11 as it relates to disability-inclusive disaster risk reduction.

Article 11 Treaty Practice as Flows of Policy Commitments and Operational Guidance

A Dynamic Notion of Article 11 Treaty Practice

Article 11 and the accompanying provisions in the CRPD framework is supporting a diverse treaty practice specifically around the protection of persons with disabilities, broadly defined as “situations of risk” in international policy commitments and frameworks. Notably, while Article 11 addresses situations of risk writ large, it is in the context of disaster risk management that Article 11 implementation is best developed. Treaty practice is less developed in the context of armed conflict or other humanitarian emergencies. Policy commitments regarding disaster planning at the international level have been accompanied by the promulgation of specific guidance and institutional commitments. The discussion below, though not exhaustive, provides an indication of the far-reaching flows of treaty practice centered on Article 11 implementation in the disaster context. It does so by applying the concept of treaty practice attuned to dynamic, flowing, interactional manifestations of change through treaty law processes (Lord et al., 2022).

The 2030 Agenda for Sustainable Development highlights the need to protect and assist persons in vulnerable situations during disasters and persons with disabilities are counted among those who face acute risk during disasters (Sustainable Development Goals, 2015). The cross-cutting nature of disaster risk reduction is mainstreamed in the SDGs, notably in the context of ending poverty through building resilience of people living in poverty and vulnerable situations for climate-related extreme events (SDG 1.5), making human settlements sustainable and inclusive through the protection of people in vulnerable situations from disasters (SDG 11.5), and combating climate change through enhancing capacities for effective climate change–related planning and management with a focus on marginalized communities (SDG 13.b). These elements of the SDGs, together with the overall disability-inclusive nature of the SDGs, including its targets and indicators, make for a disaster-inclusive and disability-inclusive SDG framework. Similarly, the New Urban Agenda (UN, 2016a, b) underscores the importance of resilient urban development that is responsive to the needs of persons with disabilities in infrastructure design and service delivery, with the emphasis on resilience indicative of both disaster and climate adaptation needs.

One of the primary international policy commitments specifically addressing disaster risk is the Sendai Framework for Disaster Risk Reduction 2015–2030 (Sendai Framework). The Sendai Framework, adopted at the Third UN World Conference on Disasters Risk Reduction, is a 15-year international blueprint for saving lives and reducing the economic impact of natural and man-made hazards. A key distinction from prior instruments of its kind is its emphasis on the need for a paradigm shift from managing disasters to managing *risk* and to addressing the underlying causes and drivers of disasters. It adopts a rights-based sustainable agenda and calls for accessibility and the inclusion of persons with disabilities in disaster risk reduction policies, all stages of disaster risk reduction planning, and data disaggregation by disability. It thus reinforces the commitments set out in the CRPD in underscoring the concept that the participation of persons with disabilities is essential in effectively managing disaster risk and designing, as well as resourcing and implementing disability-responsive disaster risk reduction policies, plans, and programs.

Disability-inclusive approaches to disaster response and recovery are reflected in other frameworks wherein disaster is specifically addressed along with other risks. For example, the Commitments to Action made at the World Humanitarian Summit held in Istanbul in 2016 include commitments to meet the needs of persons with disabilities in crisis-response operations and service delivery, to develop partnerships with disability-focused organizations, and to collect disability-disaggregated data (UN, 2016a, b). More than 150 UN Member States and UN agencies, humanitarian organizations, and civil society organizations have endorsed the Charter on Inclusion of Persons with Disabilities in Humanitarian Action.

Even more interesting and to some extent surprising is the increased attention given to disability inclusion in combating climate change within the context of international environmental law practice. The Paris Agreement (2015) of the United Nations Framework Convention on Climate Change acknowledges that States Parties should respect, promote, and consider their respective obligations on human rights, including the rights of persons with disabilities, when taking actions to address climate change (Conference of the Parties, 2015). Specifically, the preamble to the Paris Agreement notes that:

> Parties should, when taking action to address climate change, respect, promote and consider their respective obligations on human rights, the right to health, the rights of indigenous peoples, local communities, migrants, children, persons with disabilities and people in vulnerable situations and the right to development, as well as gender equality, empowerment of women and intergenerational equity (Conference of the Parties, 2015, Preamble).

Disability inclusion in disaster is also increasingly reflected in sector-specific policies and frameworks. Thus, disability-inclusive ideas are beginning to be reflected in the education sector, where disaster risk reduction focuses on school safety. It is recognized that schools – where children spend so much of their time – must be addressed in all disaster risk reduction and consistent with the UNESCO global comprehensive school safety framework (Ronoh et al., 2017). Crucially, the framework anchors key disability-inclusive disaster risk reduction principles.

Disability-Inclusive Disaster Risk Reduction Guidance

Guidance in the area of disaster risk reduction is fast emerging across UN agencies and bears the imprint of CRPD principles and disability-inclusive approaches. Guidance promulgated by actors in disaster response from the donor side (World Bank, UN) and from the implementer side of the equation (NGOs, OPDs) explicitly link core concepts in guidance documents to the CRPD. Several examples serve to demonstrate these connections.

First, among guidance documents are the voluminous guidelines adopted in an multistakeholder process, the Inter-Agency Standing Committee's *Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action* (IASC, 2019). While applicable beyond disasters, they reflect the starting point for addressing disability inclusion from a humanitarian action perspective. They explicitly embrace the CRPD as the touchstone of the guidance and also connect conceptual approaches to disability reflected in the CRPD to the operations of humanitarian assistance, including risks arising from natural disasters, climate change, and other emergencies. Of note, they adopt a twin-track approach to disability inclusion meaning disability-inclusive approaches are mainstreamed into all interventions and, in addition, targeted interventions are provided where needed. Illustratively, an effective food security intervention would consider how people with disabilities, women, older persons, and other groups can access its services, to ensure they are not further excluded. A targeted intervention may also be appropriate in some contexts, for example, a food security program that focuses on enhancing the resilience of households that include people with disabilities.

The United Nations Office for Disaster Risk Reduction (UNISDR) promulgated the World Health Organizations *Guidance Note on Disability and Emergency Risk Management for Health* in 2013 (World Health Organization, 2013).[2] The Note provides an overview of the impact of emergencies on people with disabilities and then sets out principles that should underpin practical action related to emergencies. Second, it outlines minimum actions required across sectors/clusters and defines specific disability-related actions that can be undertaken by health actors working in different areas of health care provision (e.g., injury prevention and trauma care, mental health and psychosocial support, and child health) to ensure inclusion of disability. This guidance is specifically informed by the principles and concepts set forth in the CRPD.

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[2] Other disability-inclusive resources include: GFDRR (2020) Disability-Inclusive Disaster Risk Recovery Guidance Note; GFDRR (2018) Five Actions for Disability-Inclusive Disaster Risk Management; GFDRR (2018) Disability Inclusion in Disaster Risk Management: Promising Practices and Opportunities for Enhanced Engagement.

Other guidance adopted includes the *Disability Inclusion Guidelines* published in 2017 by the United Nations Relief and Works Agency for Palestine Refugees in the Near East, UNICEF's series entitled, *Including Children with Disabilities in Humanitarian Action* and the IASC *Guidelines on Mental Health and Psychosocial Support in Emergency Settings* (United Nations Children's Fund, 2018; Inter-Agency Standing Committee Working Group, 2007).

Article 11 and Disability-Inclusive Humanitarian Action and Disaster Risk Reduction

The foregoing evidence shows flows of policy commitments reflecting a dynamic treaty practice inspiring change and movement for which there is a direct connection to Article 11 and its mandate for disaster risk reduction. Attention to the protection of persons with disabilities has also made its way into the policies of some of the largest donor organizations and many of these directly invoke the CRPD and Article 11 as the basis for policy articulation. Thus, one of the ten commitments arising from the first Global Disability Summit (2018) was the commitment regarding universal access features in post-disaster reconstruction (International Disability Summit, 2018).

More difficult, of course, is the assessment of whether and how such policy commitments are actually reflected on the ground, in the operational practice of disability-inclusive disaster risk management. Put another way, to what extent are these commitments reflected across the multitude of actors engaged in the practice of disaster risk management so much of which is not always connected to human rights treaty practices too often measured simplistically as numbers of ratifications or legislative enactments echoing a human rights commitment.

An assessment of World Bank projects funded to assist in the area of disaster risk management (DRM) provides some insights as to where Article 11 is starting to generate movement in disability-inclusive disaster risk reduction and response. In the World Bank's Empowering Elders, Women, and People with Disabilities for Resilience technical assistance program, support was provided to local communities in the Philippines and Nepal to build knowledge and capacity on inclusive preparedness and recovery efforts which include the participation of persons with disabilities (Disaster Risk Management Hub, Tokyo: Knowledge Program, 2016).[3] Co-knowledge production is an essential element of the approach, achieved through knowledge exchange with Japanese experts to replicate the "Ibasho café" approach. Ibasho cafés are run by community elders and offer an enabling space to build the resilience and agency of marginalized groups within the community.

Another World Bank–supported project, the Capacity Building on Social Inclusion (P160328) technical assistance program, works to strengthen the capacity of the Global Facility for Disaster Reduction and Recovery (GFDRR) staff, partners, and

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[3] World Bank, Empowering Elders, Women, and People with Disabilities for Resilience (P159506).

governments to identify, analyze, and incorporate social inclusion and citizen engagement into DRM projects. One of its first accomplishments report on disability inclusion in DRM capturing promising practices was published (World Bank Group & GFDRR, 2018).

This was followed by a GFDRR effort, in partnership with the Social Sustainability and Inclusion Global Practice, to provide action-oriented directions to government officials and decision-makers responsible for post-disaster recovery and reconstruction. The project resulted in the *Disability-Inclusive Disaster Risk Recovery Guidance Note* (World Bank Group & Global Facility for Disaster Reduction and Recovery, 2020).

While disability inclusion at design stage is the gold standard for disability inclusion in international cooperation programming, it is the reality that programs already underway may require and can often accommodate retrofitting where their design lacks a disability-inclusive framing. The World Bank's Lao PDR Southeast Asia Disaster Risk Management Project (P160930) did not have a disability focus in the parent project but has introduced and applied universal accessibility through additional financing (Southeast Asia Disaster Risk Management Project for Laos, 2017). Other projects have built on gender and social inclusion efforts in the parent project and expanded its scope to disability inclusion at additional financing or restructuring. This work is intended to inspire better policymaking and operational practice in operations to support disability-inclusive disaster risk reduction (World Bank Group and GFDRR, 2018).

United Nations Development Program (UNDP), critiqued for its lack of disability inclusion across its global portfolio, is starting to make some inroads in the disaster risk management space (Independent Evaluation Office, 2016). Following the adoption by the management of the recommendations set out in the Independent Evaluation Office's report on disability inclusion, policy that drives internal organizational policies and expert programming is emerging (UNDP IEO, 2016). For example, through UNDP's Digital Transformation for Resilience project, UNDP has conducted vulnerability mapping and analysis in the Philippines and Sri Lanka, engaging with organizations of persons with disabilities along with other segments of civil society and community members. In Indonesia, UNDP and Indonesia's national disaster management agency are collaborating to make the national digital geospatial platform, InaRISK, accessible for at-risk communities, inclusive of persons with disabilities to facilitate safe evacuation during a disaster (UNDP, 2021).

Some other evidence of traction under international cooperation programming is seen in the collected emerging practices of implementing partners of donor organizations. These too provide some evidence that disability-inclusive disaster risk reduction is taking hold, not only as a matter of domestic and international policy, but in terms of actual work on the ground. More evidence is needed to assess the impact of this work in detail. The OSCE, not particularly noted for its work on disability rights, is beginning to work toward disability inclusion. In 2021, it launched a project to develop online learning modules along its pillars of work. As part of the OSCE pillar on humanitarian action, it included in the online learning modules a module on disability inclusion in humanitarian action. The OSCE has been slow on the uptake of CRPD-inspired action, but the beginnings of work in the space provide some indication of possible reform.

NGOs practices in disaster-affected countries are likewise seeding disability-inclusive approaches in disaster risk contexts. Several are worthy of mention. In Bangladesh, the nongovernmental organization (NGO) CBM, the Center for Disability in Development, and Gana Unnayan Kendra assisted communities in setting up local disaster committees that included persons with disabilities as full members (Disability-Inclusive DRR Network for Asia and Pacific and CBM, n.d.). This led to the development of accessible warning mechanisms, accessible sheltering areas, and disability-inclusive evacuation drills.

In Myanmar, Malteser International conducted participatory hazard vulnerability and capacity assessments that led to the community designing plans that targeted older people, pregnant women, people with disabilities, and children (Marr et al., 2017). The project provided evidence that engagement with the diversity of the community worked to combat stigma, with community members sharing a shift in understanding about disability and thus demonstrating the critical importance of the inclusion, participation, and leadership of people with disabilities for enhancing resilience.

Schools are an important dimension of disaster preparedness work and some examples of school-focused disability-inclusive approaches are beginning to emerge. For example, in a project supported by German international cooperation, the NGO Arbeiter-Samariter-Bund Deutschland trained village-level cadres and organizations of persons with disabilities in Yogyakarta to improve disaster resilience among children with disabilities (World Bank, 2018). The cadres trained 929 out-of-school children with disabilities, 3716 family members, and 3716 neighbors of children with disabilities through safe room settings and drills. The training ensured that children with disabilities who often do not attend school are still able to access emergency preparedness training that is usually given at school.

Beyond these examples, Article 11 is working for change in sector-specific domains where disability inclusion is seriously needed. Thus, for example, the Global Shelter Cluster (GSC) Working Group on Inclusion of Persons with Disabilities, established to support a more systematic approach to disability inclusion in humanitarian shelter across the humanitarian action sector, is working on better disability inclusion in disaster response. To that end, in 2019, the GSC conducted a baseline mapping report, *Disability Inclusion in Shelter and Settlements Programming*, resulting in entry points to better advance inclusive humanitarian shelter, including: (1) ensure that vulnerability assessments identity differentiated needs of women, men, girls, and boys with disabilities; (2) develop more specific guidance and tools inclusive of infrastructure designs; (3) strengthen law and policy frameworks to institutional universal design and accredited training in government regulations; (4) integrate disability questions and engage with OPDs in shelter evaluations; and (5) adapt standardized nonfood item (NFI) catalogues and infrastructure design in partnership with OPDs to ensure context-appropriate options are available (Global Shelter Cluster Working Group, 2019).

Article 11 and Domestic Flows of Treaty Practice

Increased attention is being paid to disability inclusion at the level of domestic law and policy, an area highlighted with some frequency by the CRPD Committee in its reporting process. The CRPD Committee has called attention to the lack of consideration of the protection of persons with disabilities in risk management. The Committee has often underscored, as it did in its reporting on Bolivia, that States Parties should "take measures in the light of the Sendai Framework for Disaster Risk Reduction, for the inclusion of persons with disabilities in strategies for climate change adaptation and disaster risk reduction" (Committee on the Rights of Persons with Disabilities, 2017). Of note, it observed that the country's legal framework for disaster risk management, including Law 602/2014 relative to Risk Management or its Supreme Decree No. 2342/2015, made no reference to risk in relation to persons with disabilities.

Domestic law and policy frameworks are beginning to reflect disability-inclusive disaster, inspired both by the Sendai Framework together with Article 11 of the CRPD. Some examples point to this emerging practice. In New Zealand's report to the CRPD Committee, it reported in detail on implementation of Article 11 including measures taken in instances of risk, disaster, or emergency (New Zealand, 2011). These measures included encouraging civil defense authorities "to assess and mitigate likely impacts on disabled people in their planning and in responding to emergencies." Specific initiatives to advance disability inclusion in civil defense situations included: (a) public information resources on emergency preparedness specifically address the needs of disabled people, including a written guide produced by the Whakatane Disabilities Resource Center Trust and the Bay of Plenty Emergency Management Group; (b) resources for people with hearing impairments, to enhance the availability of civil defense emergency management information, were distributed to all local councils in 2010; and (c) public education resources for people with sight impairments are to be distributed in 2011. New Zealand further reported that, in the 2010 Christchurch earthquakes, persons with disabilities worked in partnership with civil defense to provide updates to deaf community groups, which then used their own information networks to disseminate information and, in some coverage, television updates were made accessible with captioning. Following the February 2011 earthquake, New Zealand sign language interpreters were used at civil defense briefings (New Zealand, 2011).

In Georgia, national disability legislation was adopted as a direct response to the ratification of the CRPD and the country's effort to bring its national framework into alignment with CRPD commitments. The Law on Georgia on the Rights of Persons with Disabilities legislation addresses disability inclusion in emergencies through the designation of its Emergency Management Service as responsible for ensuring that disaster panning is disability inclusive (Georgia, 2019). UNDP is supporting efforts by the Emergency Management Service to implement this component of the national disability legislation in line with Article 11 of the CRPD. The ultimate objective is to ensure that local municipalities develop emergency management plans with a disability perspective and fully engage with Georgian organizations of persons with disabilities across all phases of disaster management.

The foregoing examples suggest movement and change and a treaty practice starting to see some notes of progress. The CRPD Committee has not to date undertaken a comprehensive study of Article 11 in the disaster context. Beyond pointing to the need for States to embrace the Sendai Framework, the CRPD Committee might undertake a more concerted effort to highlight areas for prioritization. Yet the CRPD Committee is heavily reliant on information from civil society organizations and national human rights institutions and without local OPD inputs, the CRPD Committee will be unable to articulate specific opportunities for disability inclusion in this context.

Article 11 and UN Special Procedures

Another domain of action where an Article 11-inspired treaty practice is evident is in the domain of the special procedures of the UN human rights system. Much of the work of the special procedures is devoted to studies submitted to the Human Rights Council and other bodies along with country visits which allow for more detailed examination of state practice in a given domain. Less examined among the special procedures are letters of allegations are transmitted from special procedures including, for example, the UN Special Rapporteur on the rights of persons with disabilities, to States bringing to light evidence of possible treaty violations or areas of concern.

The communications procedure of special procedures can potentially amplify Article 11 in several respects. Here, a communication to the Government of Mozambique might be cited. In a letter from the UN Special Rapporteur on the rights of persons with disabilities dated 19 March 2021, the attention of the government was directed to the CRPD and, specifically, to Article 11 (OHCHR, 2021). In that case, the Special Rapporteur received information regarding allegations of human rights violations and mass displacement in Mozambique in the context of attacks and military operations in Cabo Delgado province and, further, that: “Older persons, especially those with reduced mobility and with disabilities, were reportedly often left behind in the conflict area as their families and community members were not able to carry them to safety. As a result, they remained trapped and have been caught in the fighting between the non-state armed groups and state security forces and their affiliates” (OHCHR, 2021).

Notably for showing how treaty ideas travel across treaties is the additional reference in the letter to other international commitments, including the African Union Convention for the Protection and Assistance of Internally Displaced Persons (Kampala Convention), which provides, among other things, that States are responsible for providing protection and humanitarian assistance to internally displaced persons (African Union, adopted Oct. 23, 2009, entered into force Dec. 6, 2012). It recognizes in Article 9 that protection and assistance should be provided to those with specific support needs, including older persons and persons with disabilities.

The CRPD Committee has similarly weighed in on matters of international concern relating to Article 11 in armed conflict contexts. In the CRPD Committee's communications regarding the Syrian conflict, for example, attention was drawn to the differentiated risk faced by persons with disabilities in the Syrian conflict (OHCHR, 2013). Looking ahead, there is far more scope for the UN Special Rapporteur and the CRPD Committee to give voice to the principles in the CRPD in disaster contexts as national and international actors respond to disasters.

Article 11 Treaty Practice Analysis

The review of the treaty practice generated by Article 11, and specifically its obligation to ensure the protection of persons with disabilities in disaster contexts, is beginning to emerge. It is reflected in both policy and analytical guidance and in international donor programming and national measures of implementation in disaster-affected contexts. Commitments to reach marginalized groups in the aggregate absent-specific attention to the discrete needs of persons with disabilities are increasingly recognized as deficient and unlikely to yield results. What is perhaps most encouraging is that some of these practices are reflected in large-scale, non-disability-specific programming, where such programs advance disability inclusion and include specific actions for disability inclusion as opposed to generalized outreach to "vulnerable groups."

Even where programs are not disability inclusive at the design stage, the retrofitting programming that did not at design stage adequately address the needs of persons with disabilities can be impactful. Here, the example of World Bank projects addressing design shortcomings through additional refinancing or restructuring is relevant (World Bank Group and GFDRR, 2018).

Governance structures must include institutional mechanisms to facilitate the meaningful participation of persons with disabilities in the planning and designing of recovery and reconstruction processes. The identification or designation of an agency with responsibility for coordinating and overseeing disability affairs in recovery and reconstruction is an important option. Georgia promulgated in its national disability legislation responsibility of the Emergency Management Services to give effect to the protection commitment in Article 11 of the CRPD to persons with disabilities in the context of emergencies including disasters, a practice worthy of replication.

Standards for disability inclusion in recovery and reconstruction must not only be established, but effectively communicated and in accessible formats. Accessibility, including universal design standards, must also inform physical and virtual infrastructure (such as online disaster management systems, electronic media, mobile solutions, and disaster broadcasts and communications) used for resilience and disaster management. Disability-inclusive disaster risk management through accessibility standards and universal design approaches in building codes and their implementation when “building back better” after disasters is likewise an important dimension of inclusion.

Commitments to inclusive data must inform national policies and programs and be reflected in operational standards and indicators for the inclusion of persons with disabilities in disaster preparedness, planning, and response, consistent with Article 31 of the CRPD. While disability-inclusive disaster risk reduction projects have included disability-inclusive activities, they may not have explicit indicators to monitor them. Notably, mentioning people with disabilities as potential beneficiaries alone will not facilitate collection of disaggregated beneficiary data. This means developing monitoring frameworks that include both indicators relevant for measuring disability inclusion (e.g., reconstruction of public facilities with resilient standards) and detailed descriptions (e.g., resilient standards including universal accessibility).

Post-disaster reconstruction/recovery projects can aim at both restoring essential services and improving the design standard practices. While reconstruction activities offer immediate opportunities for incorporating universal accessibility, action such as upgrading design guidelines can help introduce and activate principles of universal accessibility in a systematic way. Further, a holistic approach should be adopted that includes a range of elements including providing assistive aids, conducting disability-inclusive search and rescue, building disability-inclusive early warning system, developing disability-inclusive preparedness plans, and proposing a buddy system, among others. Supporting capacity building so that emergency management personnel include needs of persons with disabilities in resilience and disaster management operations might include the provision of technical assistance to ensure reconstruction plans post-disaster are disability inclusive.

Finally, the CRPD contemplates that specific, positive measures are required to advance convention rights. Financial and procurement are clearly elements of such positive measures. Thus, in the context of Article 11, the provision of financial support and related interventions for target households and groups that have limited ability to self-recover, including households with persons with disabilities, is important. This means the setting of standards for disability inclusion in budgeting and procurement quickly as humanitarian disasters prompt financial mechanisms and programming in response to the crisis. Standards of this nature can facilitate disability inclusion transversally, across the recovery and reconstruction process. Including principles of universal design as a condition of financial contributions and assistance by all recovery actors should likewise be an element of such approaches.

In sum, measures to advance Article 11 in the context of disasters should begin with formalized mechanisms for the ongoing participation of persons with disabilities and mainstream disability into disaster risk consultations, which further need assessments, infrastructure development, services, management plans, and policies. Participation in the form of robust consultation should likewise guide governments in their consideration of disaster or humanitarian policies or legislations, or when a community is developing an evacuation plan, an early warning system, or making decisions to combat climate change, it is crucially important to include persons with disabilities.

Toward Disability Inclusion in an International Instrument on Disaster?

While the CRPD has undoubtedly contributed to a surprising flow of treaty practice in relation to Article 11 and the protection of persons with disabilities in disaster contexts, what is less clear is the extent which this protection will be reflected in mainstream instruments of international law that addresses natural disaster. Notably, there is the prospect of a legally binding instrument on the topic of protection in disaster contexts given the work launched in 2008 by the International Law Commission on the topic of the protection of persons in the event of disaster (International Law Commission, 2016). During the ILC's 68th session, a second reading of a full set of 18 draft articles was concluded. In alignment with the mandate of the ILC to undertake studies and make recommendations on the codification and progressive development of international law, (United Nations General Assembly Resolution, 2016; International Law Commission, 2016), the ILC recommended that the General Assembly elaborate a convention on the basis of the draft articles. Notably, while the ILC draft articles reflect a rights-based approach and articulate rights and duties of States in relation to protection, interestingly, they do not enumerate groups at particular risk in the context of disasters. This is all the more surprising, perhaps, given that the current state of international human rights law is quite clear on the necessity of enumerating specific rights in relation to specific groups, lest their invisibility in legal instruments lead to invisibility in operational terms. To that extent, then, the draft articles hardly represent a current statement, much less a step forward in capturing the progressive development of international law. Rather, they reflect a step backward in reaggregating groups most at risk that the law has worked to specify – in human rights law as in international humanitarian law.

Conclusion

Article 11's ultimate purpose is to foster connections transversally – across the CRPD text and beyond – and to engender a treaty practice that activates disability rights into an emerging international disaster law regime as well as into international humanitarian law, refugee and asylum law, and international criminal law. A measure of its effect in so doing is demonstrable by assessing the many inflections it has brought about and the flow of treaty practice it is fostering through Article 11 in the disaster context.

To be sure, the challenge of making resilience and disaster risk reduction operations disability inclusive in alignment with the CRPD and other frameworks, treaties and soft law instruments, is considerable. Yet tracing flows of treaty practice from policies to programming presents a complex picture, one not discernible from a review of treaty ratification numbers or treaty body reporting. It suggests instead a treaty practice that requires reading across the treaty transversely, to explore commitments to stakeholder consultation, nondiscrimination, accessibility, international cooperation, data disaggregation, and the uptake of polices and their implementation on the ground, domestic lawmaking, national disaster planning, and the like. The foregoing account demonstrates the merits of accounting for the change that treaty practice can bring about when approached through a methodology receptive to change, connection, and flows – to speak in terms of a treaty practice conceived more like the Deleuzean notion of flow.

Cross-References

- ▶ Disaster and Climate Change-Induced Displacement of Persons with Disabilities: A Human Rights Perspective
- ▶ Disability and Disaster Risk Preparedness
- ▶ Disability and Refugee Protection
- ▶ Disability, Conflict, and Environmental Conditions: Introduction
- ▶ Inclusive Processes for Refugees with Disabilities: Improving Communication for Deaf Forced Migrants
- ▶ Widening the Scope of Non-refoulement? The CRPD and the Protection of Persons with Disabilities in Displacement
- ▶ Women and Girls with Disabilities in the Heart of the COVID-19 Crisis: Safeguarding Sex and Reproductive Health Rights

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Disability and Disaster Risk Preparedness

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Matthew Cole

Contents

Abstract

The relationship between disaster risk and social vulnerability has been thoroughly researched over the last decade by Verchick, Cutter, Smith, Brown, and others. It is well established that PWDs are at greater risk of harm from disaster events due to reduced levels of resilience concomitant with structural inequality. The following chapter outlines the role of States Parties in determining the resilience of PWDs through a vehicle that is often overlooked – land use regulation. Specifically, the chapter focuses on the way in which land use controls influence the physical, human, environmental, and social "assets" that create resilience and addresses the power of land use planning to enhance resilience and thus mitigate the risk of disaster events.

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Building Resilience

Persons with Disabilities (PWDs) are at greater risk of harm from disaster events than the remainder of the population and are up to four times more likely to die in a disaster event than persons without disabilities (Craig et al., 2019, pp. 327–356). This is because the occurrence of a disaster event is dependent upon whether a given community has the resilience to cope with a hazard, and PWDs do not have the same levels of resilience as persons without disabilities due to structural inequalities. PWD's often reside in poorer quality housing due to lower socioeconomic status which increases their exposure to natural hazards such as fire, storms, and floods. They are at greater risk of violence, sexual exploitation, abuse, and discrimination following a hazard event due to inaccessible disaster shelters (Smith et al., 2012) and sociocultural beliefs and practices (Brown et al., 2014). This correlation between social vulnerability and disaster risk has been termed "disaster justice" (Verchick, 2012), and it recognizes that disasters are a social phenomenon (Cutter et al., 2003) and that addressing underlying structural inequalities, such as educational inequality, equal access to healthcare, and racial discrimination go hand in hand with reducing disaster risk. Relevantly, this means that if the structural inequalities that make PWDs vulnerable are mitigated, disaster risk will also be reduced. To this end, both the disability and disaster risk reduction discourse share common ground: the understanding that in order to protect vulnerable groups consideration must be given to the underlying social conditions of people within a society and their relationship with the structures and institutions that govern their agency. To ameliorate vulnerability, those institutions and social structures must confer resilience in both the individual and their community. But how can this be done?

States Parties play a role in determining the resilience of persons with a disability in varying ways: healthcare, education, and welfare among the most obvious. The purpose of this chapter is to explore the role of a less prominent but equally important social institution – land use planning. Specifically, the chapter will address the role of land use planning in controlling the standards to which buildings and structures are constructed, the role of environmental attributes and social capital, and the degree of community participation in the development approval process – all of which play a significant part in influencing levels of resilience to hazards.

Section "Overview of Disaster Risk Reduction and the Inter-relationship with the CRPD" of this chapter provides an overview of disaster risk reduction and the interrelationship with the *Convention on the Rights of Persons with Disabilities* (CRPD). Section "The Role of Vulnerability Theory in Disaster Risk Reduction and Developing Resilience for Persons with Disabilities" explores how to build resilience to disaster risk through the application of vulnerability theory which identifies the types of assets that States should confer to build resilience. Section "Recognizing the Role of Land Use Planning in Enhancing Disaster Resilience for Persons with Disability" considers the way in which land use planning confers those assets with specific reference to building the resilience of PWDs. Final section concludes by suggesting a framework for land use planning that focuses upon building the resilience of PWDs for the purpose of disaster risk reduction.

Overview of Disaster Risk Reduction and the Inter-relationship with the CRPD

Disaster Risk Reduction has its origins in sociology, geography, and international development dating back to Prince (1920), White (1942), and Holling (1973), and has been promoted by the international community through the *World Conference on Disaster Risk Reduction* which first took place in Japan in 1994 (Stough and Kang, 2015), the *United Nations strategy for Disaster Risk Reduction* in 1999, the *Hyogo Framework for Action* 2005–2015, and the *Sendai Framework for Disaster Risk Reduction* 2015–2030. The field has been advanced over the last two decades by the works of Adger (2000), Wisner (1994), Blaikie (1994), Handmer and Dovers (1996), Pelling (2012), and Cutter (1996), among others. The body of research surrounding disaster risk reduction continues to grow as greater emphasis is placed on the correlation between global warming and natural disaster events. It is necessary when considering the topic of Disaster Risk Reduction to start from first principles and consider the distinction between a disaster and a hazard. In its ordinary English interpretation, the word "disaster" means:

> An event, such as a flood, fire, explosion, etc., which devastates a community and is beyond the scope of the community's own resources to manage, requiring assistance on a national scale to restore safe conditions, functioning communications and a continuing livelihood for the people. (Australian Macquarie Dictionary)

The United Nations Office of Disaster Risk Reduction (UNISDR) defines the term as:

> A serious disruption of the functioning of a community or a society involving widespread human, material, economic or environmental losses and impacts, which exceeds the ability of the affected community or society to cope using its own resources.

By distinction, the UNISDR defines the term hazard to mean:

> A dangerous phenomenon, substance, human activity or condition that may cause loss of life, injury or other health impacts, property damage, loss of livelihoods and services, social and economic disruption, or environmental damage.

Key in these definitions are two messages, the first being that the scope of what constitutes a hazard is broad. Hazards present in varying forms that can be divided into two broad categories: "natural hazards" and "technological," or "anthropogenic hazards." Natural hazards refer to naturally occurring phenomena which are caused by slow or rapid onset events and can be further subdivided into the categories of "geophysical hazards" such as volcanic activity and earthquakes; "climatological hazards" such as drought, bushfire, and heatwave; "biological hazards" including plagues and viral pandemics such as Covid-19; and "hydrological hazards" such as floods (Shi, 2019). Technological or anthropogenic hazards on the other hand are those hazards caused by human beings including wars, terrorism, and industrial accidents.

The second message that one can take from the above definitions is that a disaster is not merely the happening of a hazard or accident, but the culmination of the occurrence of that hazard, and the inability of human beings to respond to it. In this way, all disasters are anthropogenic. A bushfire, flood, drought, or hurricane are simply natural phenomena without any subsequent destruction to human life, property, or infrastructure, which is not possible without some element of human failure such as the poor location of settlements, inappropriate height of buildings, or insufficient evacuation routes. Accordingly, when we are talking about "types of disaster" what we actually mean is "types of hazard." When one understands the anthropogenic nature of a disaster event it then becomes possible to start identifying the causal factors of those events and to begin looking for appropriate mechanisms for mitigation. Furthermore, if we accept the premise that there is a direct nexus between human capabilities, that is, the various functionings that a person (and community at large) is able to achieve (Robeyns, 2005) and the magnitude of a disaster event, we can then begin to explore the types of capabilities that need to be enhanced in order to reduce disaster risk.

It is at this juncture – the intersection between human capabilities and causation of disaster events – that there is a clear interrelationship between the disaster risk reduction discourse and the *Convention of the Rights of Persons with Disabilities* (CRPD). A key function of the CRPD is to promote and enhance the capabilities of people with Disabilities. This is evident on examination of Article 9 – "Accessibility" which requires:

> States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:
> (a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;
> (b) Information, communications and other services, including electronic services and emergency services.

The Article goes on to require that States Parties, inter alia, take appropriate measures to develop minimum standards and guidelines for the accessibility of facilities and services; to promote appropriate forms of assistance and support to persons with disabilities; and to provide support for access to information, but also that private entities that offer facilities and services take into account all aspects of accessibility for PWDs (CRPD, Article 9). Accordingly, Article 9 "not only imposes widespread positive obligations on States Parties, but it also requires the private sector to take into account accessibility considerations" (Broderick, 2020).

The accessibility norm is enshrined throughout the CRPD. It first appears in the Preamble, then again under the general principles at Article 3, in the general obligations, and also throughout several of the substantive Articles, including in the context of the provision of accessible information (CRPD, Article 21), access to work and employment (CRPD, Article 27), and participation in political and public life (CRPD, Article 29). Accessibility is clearly viewed as a fundamental pillar to ensuring equality for PWDs. Indeed, the United Nations General Assembly has long identified accessibility as a priority in promoting equality of opportunity for persons with disabilities (General Assembly resolution 52/82). As Broderick states (2020, p 399):

> This progressive understanding of equality in the CRPD aligns with the 'social-contextual understanding of disability' that underpins the Convention and its accessibility obligations. This version of the social model views disability as an interaction between persons with impairments and widespread barriers in society (physical barriers, as well as legal and attitudinal barriers, among others). Together with the human rights model of disability that underpins the CRPD, this has resulted in an acknowledgment of the fact that a barrier-free society is essential to ensuring full and effective participation and inclusion of persons with disabilities, something which will require a significant reallocation of resources.

This approach mirrors the socio-environmental lens of the Disaster Risk Reduction discourse, which accounts for the interaction between people and their environment. While accessibility is about building the capability of PWDs so that they have greater autonomy over their environment, so too, disaster risk reduction promotes the building of "resilience" which, put another way, is about enhancing the capabilities of people so that they may be less vulnerable to a hazard when it occurs, therefore reducing the risk of a disaster event. It follows that building the capabilities of people within a community with the intent of ameliorating that community's vulnerability serves the dual purpose of both reducing disability and reducing disaster risk. Recognition of this need to enhance capabilities gives rise to an exploration of the most efficacious approach to do so, which is where an application of vulnerability theory comes to the fore.

The Role of Vulnerability Theory in Disaster Risk Reduction and Developing Resilience for Persons with Disabilities

The UNISDR explains disaster risk using the equation: *risk = hazard x exposure x vulnerability* to explain that disaster risk is "considered as the combination of the severity and frequency of a hazard, the numbers of people and assets exposed to the hazard, and their vulnerability to damage" (Global Assessment Report on Disaster Risk Reduction, 2015). In other words, it is only when a hazard combines with pre-existing human vulnerabilities that disaster events occur. Furthermore, the distinction between a mere hazard and a disaster is dependent upon the ability of a community to withstand the disruption caused by the hazard. Moreover, disasters are not blind to structural inequality; they intensify pre-existing social, economic, and physical vulnerabilities. If one has a solid house that is able to withstand a hazard and is surrounded by adequate and well planned infrastructure, and have the support of a strong social network then they are less vulnerable to the hazard when it occurs, and if the same is true of all of the members of one's community, the hazard is less likely to become a disaster. By corollary, if one is more vulnerable to the hazard because they lack the capability necessary to provide the resilience to withstand it, then the risk of disaster is greater. Moreover, if a disaster ensues it is likely to compound any pre-existing vulnerability leading to increased social inequality because one will not receive the extra assistance needed to recover economically and will subsequently fall into greater dependency.

Accordingly, central to the magnitude of a disaster event is a recognition of the level of vulnerability in a given society. Vulnerability is broadly defined to mean the potential for loss (Cutter, 1996). The most vulnerable are considered those who are the most exposed to loss and who possess a limited capacity to recover from that loss (Bohle et al., 1994). There is a bifurcation in the epistemological approaches taken to the study of vulnerability: it is either analyzed in the context of the loss incurred by the individual (termed individual vulnerability) or the loss incurred by society at large (termed social vulnerability) (Cutter, 1996, p 530). Importantly, vulnerability is to be seen "not as a property of social groups or individuals, but is embedded in complex social relations and processes" (Bankoff et al., 2013) – at its core it is a socio-political concept which is dependent upon the relationship that people have with their environment and the forces and institutions that shape that relationship. Vulnerability Theory posits that the distribution of assets necessary to mitigate and ameliorate the physical fragility universal to the human condition is the proper reference point for legal discourse and substantive equality (Fineman, 2008). The approach has considerable utility for studies on disaster risk reduction because it incorporates a dimension of sociomateriality fundamental to building resilience to natural hazards, which is a core tenant of the disaster risk reduction discourse.

Fineman's "Vulnerability Theory" came to prominence following publication of her article "The Vulnerable Subject: Anchoring Equality in the Human Condition" (Fineman, 2008). The theory posits that vulnerability is to be understood not in the context of specific human characteristics such as sex, age, race, disability, or socioeconomic status, but as concomitant with the fragility of our human embodiment and which results in all persons being constantly and unavoidably susceptible to harmful events beyond our control (Fineman, 2010). These harmful events include disease, injury, and environmental hazards such as bushfires, earthquakes floods, and pandemics (Fineman, 2008).

The antipole of vulnerability, Fineman claims, is not invulnerability, for there can be no such thing (Fineman, 2010), but resilience: not to be understood in the scientific sense of "bouncing back" or "resiling" from adversity in a way that restores the equilibrium, but as possessing the tools necessary to mitigate and ameliorate those aspects of the human condition that makes us susceptible to harm (Fineman, 2010). It is argued that the level of resilience that one attains throughout the stages of their life cycle is relative to their relationship with the various institutions that confer the "assets" necessary to foster that resilience (Fineman, 2010) and inequality and injustice manifests in the unequal distribution of those assets. It follows that the core premise of Vulnerability Theory is that substantive equality is achieved through "equality of resilience" (Mboya, 2018).

This core argument provides the platform to position the State as responsible for the vulnerable subject, to critique its role in the administration of asset conferring institutions, and to demand that it takes a more responsive role in building resilience. In this way, the theory advocates for more equitable institutional responses to socioeconomic problems. Vulnerability Theory challenges the notion of "formal equality" and the predominant liberal legal paradigm in which the legal subject at the core of the juridical order is the autonomous and rational individual. Vulnerability theory challenges this traditional notion to claim that the proper starting point for legal discourse is in fact the "vulnerable subject": the subject embodied in its sociomaterial context, and dependent upon institutions and human relationships (Mboya, 2018). It contends that the "mythos" (Grear, 2014) of the liberal subject exacerbates injustice by masking privilege, failing to acknowledge our dependency on human relationships and social arrangements, and benefiting certain interest groups within society to the detriment of others. The paradigm of the liberal subject gives purchase to the claim that inequalities are justified by reference to individual responsibility and the meritocracy of the free market. Whereas liberal theory fails to recognize that we are all born with differing levels of capacity as a result of varying factors such as our geophysical location on earth, our age and mobility, our sex and socioeconomic status. Vulnerability Theory underscores the embodiment of the individual and the importance of sociomateriality (Fineman and Grear, 2016). Relevantly, the theory recognizes the law as a vehicle by which the State shapes, controls, and reinforces those asset-conferring institutions (Fineman & Grear, 2016). But also the power of the law as an agent to control and mitigate – or exacerbate – our vulnerability.

Fundamental to this claim is an understanding of exactly what assets are necessary to mitigate disaster events and how it is that land use planning confers them. In describing the assets fundamental to building resilience, Fineman draws upon the work of Peadar Kirby (Kirby, 2006) to posit that there are four key asset classes: physical assets, human assets, social assets, and environmental assets (Kirby, 2006). *Physical assets* are "those physical and material goods that we own or command that determine our quality of life and cushion us in the face of disaster events" (Kirby, 2006). In the context of disaster and flood risk reduction, these assets include land, dwellings, and infrastructure such as roads, hospitals, stormwater pipelines and drainage infrastructure, specific flood mitigation infrastructure such as levies and dams, and emergency services.

Human Assets are described as those innate or developed abilities to make the most of a given situation (Kirby, 2006). The concept of human assets draws upon the work of Sen and Nussbaum's Capabilities Approach which focuses upon the "functioning's" of human beings (Nussbaum, 2001). Mobility, health, education, and decision-making, are clear examples of human assets that influence resilience to a hazard. Older and more frail individuals and individuals with physical and mental disabilities have reduced capability to evacuate during a disaster event. Likewise, individuals who are not educated as to the risks associated with hazards are less able to avoid those risks and more susceptible to harm. In addition, people who are unable to speak English cannot read visual flood warning signs or understand verbal communications to evacuate flood prone areas or take advised precautionary measures.

Social Assets are described as those networks of relationships from which we gain support and strength, such as family, friends, cultural groups, and associations (Nussbaum, 2001). The concept of "social vulnerability" in the disaster risk reduction context has been explored in depth by Cutter who emphasizes the importance of "social capital" in building resilience to hazards (Cutter et al., 2003).

The final category is *Environmental Assets*, which are those assets that address issues of the natural and built environment, including bio-diversity, pollution, and natural resources that impact upon individuals and their communities (Kirby, 2006). Environmental assets have particular relevance in the context of disaster risk reduction because of the correlation between the management of natural resources and the occurrence of natural hazards. For example, the preservation of wetlands and the prohibition of development on riparian lands has the potential to reduce the severity of flooding (Lee & Huang, 2018); the transition to clean energy and net zero emissions will reduce the impacts of climate change and sea level rise; and the placement of hazardous development away from populated areas reduces the risk of impact from industrial hazard and pollution. Consider also the intersectionality between physical and environmental assets. The permissibility of development that contributes to the effects of climate change and rising sea levels impacts upon coastal flood risk. In 2019, the New South Wales Land and Environment Court held that a development application for a coal mine was to be refused on the basis of unacceptable scope three (downstream) greenhouse gas emissions, meaning that the project would have unacceptable environmental impacts because the coal that was being mined from the ground in New South Wales would result in unacceptable emissions when it was used for electricity generation in a foreign country. This is an example of the way in which a physical asset – such as a coal mine – has the ability to impact upon environmental assets, and demonstrates the power of land use planning to influence the distribution of environmental assets that have an impact on disaster risk.

The next part in this chapter looks closer at the way in which land use planning can enhance the resilience of PWD's by focusing resources and attention to these four asset classes.

Recognizing the Role of Land Use Planning in Enhancing Disaster Resilience for Persons with Disability

Land use planning shapes the communities in which we live, not just physically by determining the location and built standard of the structures which we occupy, but also environmentally through the preservation of biodiversity and control of environmental impacts, as well as socially through the placement of community services and spaces that create social cohesion. By governing these aspects of our lives, land use planning controls the level of individual and community vulnerability to hazards and in doing so determines the occurrence and magnitude of disaster events.

However, we should not make the assumption that all States have adequate land use planning systems, indeed many developing, and even many developed, States Parties and jurisdictions do not. Consider for example the nation of Nepal which in April 2015 was struck with a magnitude 7.8 earthquake that killed nearly 9000 people and either partly or completely damaged over 900,000 buildings (Pokharel & Goldsworthy, 2017). Research following the earthquake in 2015 found that although an earthquake design code was present in Nepal, it was not mandatory in every part of the country nor was it sufficiently enforced. More than 80% of earthquake risk comes from vulnerable buildings (Guragain et al., 2018) and yet buildings in Nepal were being constructed by individuals based on their own needs and budget without consulting engineers (Guragain et al., 2018). By way of further example, the lack of sufficient land use planning regulation has also been found to contribute to flood risk in Sri Lanka (Dissanayake et al., 2018) and Ghana (Tasantab, 2019), bushfire risk in Australia (Buxton et al., 2011), landslide in Sierra Leone (Guzzetti et al., 1999), and Tsunami in Japan (Nakasu et al., 2018). Accordingly, it is first necessary to acknowledge the need for adequate land use planning, and that its omission can magnify the impacts of disaster events. Secondly, we must ask ourselves what makes a sufficient land use planning system and how can we improve them to build disaster resilience for PWDs and the broader community? It is contended that the answer to that question lies in analyzing the way in which land use planning systems distribute the aforementioned four key assets that build resilience.

Physical Assets

Land use planning plays a role in determining the distribution of physical assets by controlling whether, and the way in which, land is developed and utilized. Land use planning distributes physical assets in two main ways, the first is through *zoning* and the second is by *imposing standards* on development which together determine the positioning of structures relative to hazards, the standard to which those structures must be built and any measures that must be implemented to mitigate any potential hazards, thereby controlling the degree of exposure and the level of vulnerability to a hazard for the user of the development.

The zoning of land involves a process of determining what development is permissible in a given location. For example, a zoning process may determine the location of residential settlements, the location of hospitals and aged care facilities, and the location of emergency services. Residential accommodation and care facilities that accommodate PWDs should not be located in close proximity to hazards such as on flood prone land or bushfire prone land. Equally, emergency services should be located in close proximity to residential settlements that are susceptible to hazards. So too, consideration needs to be given to the zoning of land as open space to create buffers between natural hazards, and evacuation points. Likewise, zoning decisions which sterilize riparian corridors from development help to mitigate flood risk and the amount of infill development permitted on a floodplain has the potential to alter flood levels by displacing water whilst allocating open space for flood storage can mitigate against rising flood levels.

The imposition of standards on development is the second key way in which physical assets are conferred through land use planning. After a zoning process has determined the type of development that is permissible in a given location, land use regulations impose standards on that development to ensure that it is constructed to agreed specifications. The standard to which development is built has particular implications for PWDs. Buildings which incorporate universal design improve the mobility and accessibility of PWDs which in turn affords them greater capability to evacuate and seek shelter from hazards. The standard of infrastructure is also relevant: Roads and bridges need to be adequately built to withstand hazards and facilitate evacuation. Sufficient roads also impact upon evacuation times and the accessibility of emergency services vehicles.

To illustrate the impacts of both zoning and the imposition of standards on development, consider a residential care facility accommodating PWDs located on flood prone land with ground floor living quarters and which is isolated from emergency services. The occupants of that facility are going to be considerably more vulnerable to a flooding hazard than a facility located above the flood level with accessible design features, provisions to shelter in place during a flood event, and which is in close proximity to emergency services (Yeo, 2015). The difference is effective strategic planning which recognizes the need to distribute physical assets (in this case the aged care facility and support services) in a way which minimizes vulnerability to hazards through both consideration of proximity to the hazard and emergency services (through zoning) and the imposition of suitable standards on the development.

Human Assets

Land Use Planning also confers human assets in two key ways. First by ensuring that development is built to a sufficient standard to afford PWDs with autonomy over their mobility during a hazard event. Ensuring that the built environment is equipped with appropriate visual and hearing aids, appropriate alert and alarm systems, inclusive access and egress to buildings, accessibility of shelters and evacuation centers and adequate transportation are all examples of the way in which the built environment can affect the capability of PWDs to respond to a hazard.

The second way that land use planning confers human assets is by controlling the level of self-determination that PWDs have over the decisions made in respect of their environment. Effective land use planning provides for a process of community consultation before development is approved, affording community members with the right to object to development, as well as to advocate for the standards of development. Without the capacity to advocate for or against development, the needs of PWDs can be overlooked. As Young (199o) states:

> decision-making processes in cities and towns can often reproduce and exacerbate inequalities and oppressions. They also produce or reinforce segregations and exclusions within cities and between cities and towns, which contribute to exploitation and marginalisation.

Accordingly, land use planning regimes confer capability upon PWDs by enabling mobility, accessibility, and self-determination through participation in decision-making.

Social Assets

Land use planning plays a significant role in building social capital and fostering inclusivity. Inclusive spaces where community members can gather and socialize and form social networks such as parks and town squares, community halls, function centers, and sporting fields are all public spaces which bring people together and build social capital. It is vital that these spaces also accommodate PWDs so that they are not excluded from this process of social cohesion. As Han et al. have demonstrated, the stronger social capital a community has built up, the fewer lives are lost in times of disaster (Han et al., 2019). When disasters occur, social capital can actually grow and serves as the primary resource for a community to prepare for, respond to, and recover from a disaster event (Han et al., 2019).

Land use planning controls the distribution of social capital in several ways. Firstly, by mandating the design and fragmentation of settlements and the positioning of physical assets such as parks and community facilities. Depending on its effectiveness, land use planning can play a fundamental role in either dislocating or co-locating social networks. It can direct proponents as to which social impacts are relevant for consideration when designing a development. By way of example, in the jurisdiction of New South Wales, a proponent is required to take into consideration comprehensive "Social Impact Assessment Guidelines" when preparing an Environmental Impact Statement (EIS) to accompany a development application for a major project. Those guidelines require a proponent to consider the social impacts of their project upon vulnerable or marginalized people, including PWDs (NSW DPIE, 2021). Those social impacts are categorized to include impacts to way of life: meaning how people get around and interact on a day-to-day basis; community cohesion and people's sense of place; accessibility; culture; health and wellbeing: including mental health; impacts to surroundings and amenity; and livelihood: including the impacts of a project on person's capacity to sustain themselves through employment (NSW DPIE, 2021).

In determining whether to approve development, land use planning regimes can require decision-makers to give consideration to the suitability of a site and the social impacts of the development (*Environmental Planning and Assessment Act 1979*, s 4.15(b) and (c)) and in the absence of sufficient recreational and communal space, a development can be refused. In addition, land use planning regimes in certain jurisdictions may also require a proponent to contribute funds to the creation or upkeep of parks and communal spaces through agreements with government, and the imposition of conditions on the approval of their developments (*Environmental Planning and Assessment Act 1979*, s 7.11). In this way, land use planning regimes are a key lever in distributing the social assets that are necessary to build resilience.

Environmental Assets

The environment has been identified as the primary factor that improves or disadvantages the lives of people with disabilities (Hahn, 1986). Aspects of the natural environment such as geographic location and topography can hinder levels of resilience f0r PWDs. For example, PWDs in rural communities are often isolated from appropriate support services by distance and transport constraints and residential settlements that accommodate PWDs should be located on topography that reduces their exposure to a hazard, such as on a higher ground above flood levels and safe distances from bushfire prone land. Consideration also needs to be given to the positioning of hazardous development relative to communities that accommodate PWDs. One need only take the example of the Vale Brumadhino dam disaster in Brazil in 2019 – in which a mine tailings dam failed killing 270 people in the rural village of Córrego do Feijão located downriver (Rotta et al., 2020) – to appreciate the correlation between natural assets (in that case the river) and their capacity to exacerbate a hazard. Land use planning has a role to play in factoring these aspects of the natural environment into the planning of cities and the approval of developments so that natural assets are used to the advantage of PWDs to ameliorate – and not exacerbate – the risks associated with hazards.

Conclusion

If we accept the premise that disasters are indeed a social phenomenon and that structural inequality and social vulnerability plays a fundamental role in the causation and magnitude of disaster events, it follows that disaster risk reduction must address those underlying pre-existing social inequalities that exacerbate vulnerability. As Fineman claims in her vulnerability theory we as human beings are all vulnerable in some way as a result of our physical embodiment, but “because we are positioned differently within a web of economic and institutional relationships, our vulnerabilities range in magnitude and potential at the individual level” (Fineman, 2008, p.10) and this is particularly true of PWDs. The problem then is those institutional relationships and structural inequalities.

Recognizing the problem for which we are trying to solve, the question is then one of how. How do we build the resilience of PWDs to mitigate their disaster risk? The answer is by looking to those social institutions and vehicles that confer the physical, human, social, and environmental assets that build their resilience. States Parties control many of those social institutions and this provides a platform to position the State as responsible for the vulnerable subject and to demand that it take a more responsive role in building resilience.

This chapter has demonstrated that land use planning is one very powerful vehicle at the disposal of States Parties to confer resilience on PWDs. It controls the positioning and standards of buildings and structures such as roads and bridges that are needed to withstand hazard events and provide adequate shelter. It also controls the degree of mobility and accessibility of PWDs to support services, levels of social capital, and self-determination through participation in decision-making, all of which enhance the capabilities of PWDs and the degree of agency that they have over their environment.

As effective as land use planning can be in building resilience, equally it can exacerbate disaster risk through poor decisions that fail to account for vulnerable people. Unfortunately, poor land use planning decisions that fail to account for PWDs and vulnerable groups are all too common. Too often the vested interests of developers take precedence over the interests of the more marginalized and underprivileged sectors of our society and this plays out in the way our cities and towns are planned and developed, reinforcing disadvantage and structural inequality. As Anguelovski et al. (2016) state:

> land use plans in the name of climate adaptation or resilience can produce maladaptive outcomes for historically marginalized residents through two types of injustices: acts of commission and acts of omission. We find acts of commission when infrastructure investments, land use regulations, or new protected areas disproportionately affect or displace disadvantaged groups. Conversely, acts of omission refer to plans that protect economically valuable areas over low-income or minority neighborhoods, frame adaptation as a private responsibility rather than a public good, or fail to involve affected communities in the process.

There must be a shift in the focus of land use planning systems; they must be viewed through the lens of the vulnerable subject and look past conventional objectives and the power dynamics of vested interest groups that control power, to instead re-position the primary focus on building individual and community resilience to ameliorate vulnerability and reduce disaster risk.

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Disability and Refugee Protection

Towards a Formalised Approach

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Mary E. Crock

Contents

Abstract

Recent years have seen major change in the way vulnerable migrants – including persons with disabilities – have been recognized as subjects of international law deserving of attention and protection in disaster situations. This chapter traces the recent evolution of international law and policy governing the rights of persons with disabilities living as refugees and humanitarian migrants, bereft of state protection. It examines UN and agency-level responses to the UN Convention on the Rights of Persons with Disabilities (CRPD) in the management of persons displaced by human conflict. The COVID-19 pandemic both disrupted asylum law and amplified inequalities and inequity. The chapter explores key elements of the Refugee Convention as it applies to persons with disabilities, using the concept of "reasonable accommodation" enshrined in Art 2 and Art 5(3) of the CRPD adopted as a unifying theme. It examines how obligations to accommodate for disability should alter processes to determine refugee status. The chapter

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concludes by discussing durable solutions for refugees with disabilities and international human rights treaty law.

Introduction: Towards Inclusive Protection in Conflict-Induced Displacement

The phenomenon of individuals crossing borders to escape armed conflict and other forms of catastrophic civil unrest has attracted a great deal of attention in international law. In some ways, the Refugee Convention (as amended) represents the strongest of all the human rights treaties: it has certainly become integral to human rights protection (Chetail, 2021). A remarkable feature of the international legal landscape is how little concern was shown for discreetly and uniquely vulnerable groups in displacement, namely women, children, and persons with disabilities. Conflict and disaster obviously cause death and disabilities in such groups.[1] Yet it is only in recent years that the United Nations agencies, including UNHCR, have recognized that particular strategies are required to provide equal protection to different categories of refugees and displaced persons.[2] Prompted by evidence that UNHCR was identifying only very small numbers of refugees as persons with disabilities, research has shown that it is wrong to assume that these people are not able to travel and so are underrepresented in displaced populations.[3] The findings of the WHO (2011) global survey[4] apply absolutely to refugee groups. In fact, a 2014 HelpAge and Handicap International survey found that close to 30% – twice the WHO average – of persons fleeing the conflict in Syria that year were persons with "special needs"/disabilities. This figure jumped to 77% for elderly refugees.[5] As others in this section attest, the invisibility of persons with disability is endemic in all displacement contexts, seemingly whatever the cause of displacement.

This chapter traces the recent evolution of international law and policy governing the rights of persons with disabilities who are living as refugees and humanitarian migrants. "Refugees" in this sense are defined by the Refugee Convention (1954) as persons outside their countries of habitual residence, bereft of state protection. These problems also inhere in humanitarian migrants insofar as repatriation carries a risk of persecution or abuse.[6] The chapter begins in Part 2 by examining UN and agency-level responses to the UN Convention on the Rights of Persons with Disabilities (CRPD) in the management of persons displaced by human conflict. Issues around refugees and

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[1] IDMC (2021).

[2] For the breadth of change, see Costello et al. (2021).

[3] Crock et al. (2017), ch 1, ch 4; and Crock et al. (2014).

[4] WHO (2008), 34. WHO and the World Bank, (2001), ch 2. WHO researchers found that approximately 2.9% of any population can be expected to be persons with severe disabilities, with a further 12.4% having moderate or long-term disabilities. Xref other chapters.

[5] See HelpAge International and Handicap International, (2014).

[6] See further Motz (2020). On refugee law generally, see Hathaway and Foster (2014) and Goodwin-Gill and McAdam (2021).

humanitarian migration have attracted unique and specify policy initiatives. As explored throughout this chapter, the COVID-19 pandemic both disrupted asylum law and amplified inequalities and inequity. Part 3 explores key elements of the Refugee Convention as it does and should apply to persons with disabilities. I use as a unifying theme the concept of "reasonable accommodation" enshrined in Art 2 and Art 5(3) of the CRPD. This is complemented by the work of Stephanie Motz in ► Chap. 88, "Widening the Scope of Non-refoulement? The CRPD and the Protection of Persons with Disabilities in Displacement," who examines the extent to which the CRPD introduces a separate obligation not to return persons with disabilities to a place where they could face persecution or serious human rights abuse. The chapter continues in Part 4 with an examination of how obligations to accommodate for disability should alter processes to determine refugee status. It concludes by discussing durable solutions for refugees with disabilities and international human rights treaty law.

The CRPD and International Protection Initiatives

To set the scene for a detailed discussion of disability and refugee law, this section begins with an overview of how the CRPD changed attitudes, assumptions, and, ultimately, policy settings within key UN agencies. It captures the responses of UNHCR and the International Organization of Migration (IOM) before touching lightly on other international initiatives done following mass migration events in and after 2015. Some of these are the subject of more detailed discussion in Xref.

A pervasive problem for refugees with disabilities seems to have been attitudes that conflate impairments with medical problems (see Arbour, 2006, para 11). UNHCR's, 2004 Resettlement Handbook (UNHCR, 2004, para 4.4.4) stands as an example in point. This document prioritized the evacuation of persons with acute conditions (including disabilities) but directed that refugees with disabilities considered "stable" should not be proposed for resettlement.[7] The revolution wrought by the CRPD is that the Convention rejected categorically the "medical model"[8] by defining disability in Art 1 as an inability to participate in society. Barriers to participation can be caused by long-term physical, mental, intellectual, or sensory impairments, but also by (prejudicial and exclusionary) attitudes – and by a failure to accommodate for impairments. Article 5(3) then requires States parties to make "reasonable accommodations" for persons with disabilities. These are defined in Art 2 as:

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[7] Paragraph 4.4.4 of the 2004 handbook read:

> Disabled refugees who are well-adjusted to their disability and are functioning at a satisfactory level are generally not to be considered for resettlement. . . . Only when such disabilities are untreatable locally, and when they seriously threaten the person's safety or quality of life, should resettlement be explored.

[8] Shakespeare (2010), 266–73.

> . . . necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms. . .

As Janet Lord explains in ► Chap. 88, "Widening the Scope of Non-refoulement? The CRPD and the Protection of Persons with Disabilities in Displacement," the second major advance made by the CRPD is the express recognition in Art 11 that the rights of persons with disabilities cannot be suspended in situations of risk, including situations of armed conflict, humanitarian emergencies, and the occurrence of natural disasters.

The Committee overseeing the (CRPD) acknowledged from the outset that the Convention extends beyond citizens, obliging state parties to uphold the rights of refugees and displaced persons (CRPD Committee, 2012, para 16). The Committee includes questions on Article 11 in its review of countries and has frequently offered criticisms of state policies and practice as they affect refugees and migrants with disabilities.[9]

State parties to the Refugee Convention responded to the CRPD with UNHCR Ex Com Conclusion No 110 in 2010. The following year UNHCR issued the "Need to Know Guidance" (UNHCR, 2011b) to encourage field workers to both identify refugees with disabilities and improve targeted assistance (Crock et al., 2017 ch 2, 4). It also revised its Resettlement Handbook to make the document more inclusive (UNHCR, 2011a). Most importantly, after some time spent in research and consultations, UNHCR altered the systems used to register and verify details about persons in its care. This had the effect of bringing its accounting of disabilities among "populations of concern" much closer to WHO estimates (see Crock et al., 2017, Ch 4).

The impact of the CRPD on international and transnational initiatives involving forced migrants is interesting to trace. Suffice to say that the response was not immediate. In 2012, the IOM's *Operational Framework* made no special reference to persons with disabilities (IOM, 2012). The Nansen Initiative on Disaster-Induced Cross-Border Displacement (Nansen Initiative, 2015) made little reference to persons with disabilities in its initial "Protection Agenda." However, 2015 seems to have marked a turning point following the Fukushima disaster in Japan (Xref) and a civil war in Syria generating unprecedented migration flows across Europe. The IOM embraced change as it moved to acquire the status of a UN body (UNGA, 2017, 16–17). Its *Migrants in Countries in Crisis Initiative* (IOM, 2016) called for planning to assist "particularly vulnerable populations" and established guidelines that reference the needs of migrants with physical, visual, or auditory impairments. The subsequent World Humanitarian Summit in Istanbul lead to the creation of the Charter on Inclusion of Persons with Disabilities (2016) which included operational commitments to nondiscrimination and inclusive policy and practice. A parallel summit in North America produced the New York Declaration (2016) for Refugees and Migrants which makes similar calls on States to acknowledge the needs of persons with disabilities in displacement (at [58]).

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[9] See International Disability Alliance; Crock (2021), Part 4. Xref Lord Ch.

By the time the Global Compacts on Migration and Refugees were concluded in 2018, the rights of refugees and migrants with disabilities were firmly on the mainstream agenda.[10] References to disability in the Global Compacts are echoed in revisions to various standard setting and guidance documents used by the major humanitarian agencies, including UNHCR. These include the 2018 ADCAP (2016) *Minimum Standards for Age and Disability Inclusion in Humanitarian Action*; the UN Inter-Agency Standing Committee (IASC) Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action and Multi-cluster/sector Initial Rapid Needs Assessment tool (IASC, 2015); and the so-called "Grand Bargain" stream convened to improve and integrate needs assessment techniques.[11]

However positive these developments, it is not clear that refugees with disabilities were (or could be) given priority treatment when the COVID-19 pandemic swept the world in 2020–2021. In April 2020, UNHCR estimated that over 71 million refugees, asylum seekers, and internally displaced persons were at particular risk because of their crowded and unsanitary living conditions. Approximately 167 countries had fully or partially closed their borders to contain the virus. Of these, 57 made no exception for asylum seekers and refugees approved for resettlement.[12] While refugees around the world moved to organize,[13] UNHCR issued a special guidance calling on states to consider the rights of vulnerable refugees.[14] The CRPD Committee) (CRPD Joint statement, 2020) and the Committee on Economic, Social and Cultural Rights (CESCR, 2020), and the Human Rights Committee (2020) issued similar exhortations to states to respect the human rights of persons with disabilities within vulnerable populations. As we turn to consider the specific rights of refugees with disabilities, it will be seen that the global pandemic had considerable impact on the realization of those rights.

Rights to Protection: Disability and Refugee Status

UNHCR and other relief agencies can and often do proceed on the assumption that whole populations of displaced persons are "refugees" or "persons of concern" attracting entitlement to relief.[15] This "mandate" approach will not apply where an individual wishes either to avoid expulsion from a country of asylum or to be included in resettlement programs. Here the formal definition of refugee becomes

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[10] See Chetail ch 6299 ff; Chetail (2019).

[11] For other initiatives, see Crock (2021) Part 2, discussing UN reforms to collecting data disaggregated to capture vulnerabilities, and the "Grand Bargain" process relating to needs assessment techniques (Agenda For Humanity, n.d.).

[12] UNHCR (2020a); Triggs (2020), 368; Bond et al. (2020), 692; Chetail (2020).

[13] See Alio et al. (2020).

[14] UNHCR (2020b).

[15] See Milner and Ramasubramanyam (2021), 192ff.

critically important. Article 1A(2) of the Refugee Convention, as amended by the Refugee Protocol (1967), defines a refugee as a person who:

> . . .owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country.

In this short survey piece, it is not possible to explore all elements of this much litigated and scrutinized provision.[16] Rather, key elements of the definition will be examined to articulate the benefits (of being recognized as a refugee) and challenges (in gaining recognition) presented for persons with disabilities in displacement.

Well-Founded Fear

Simply being a person with disabilities displaced internationally by war or disaster does not make a person a refugee at law. The first requirement of Art 1A(2) is that a refugee demonstrate a "well-founded fear" of returning to their country. This phrase underpins an entire industry devoted to examining "country information," described as the objective aspect making a fear "well-founded" (Chan Yee Kin v Minister for Immigration and Ethnic Affairs, 1989; Hathaway and Foster, Ch 2 and 3). However, at least in theory, a claimant must also be able to articulate a subjective state of fear. For persons with psychosocial and severe physical disabilities – as with young children who lack capacity – this can pose a critical barrier to protection. UNHCR, some courts, and many commentators argue that lack of capacity should simply mean a shift of focus from subjective to objective evidence of fear.[17] However, this approach is not universally accepted. As Motz (2015) argues, the "reasonable accommodation" requirement in Art 5(3) of the CRPD should operate to lighten the burden of proof that would otherwise lie with an applicant. Just as baseless fear must be moderated by objective evidence of danger, so too should the "fear-less" applicant have their claims considered in context.[18]

Persecution

Although not defined in the Refugee Convention, persecution is broadly understood in refugee law to comprise three elements: discrimination or targeting; serious harm; and the failure of state protection.[19] Together, these operate to exclude from

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[16] See Hathaway and Foster (2014) and Goodwin-Gill and McAdam (2021).

[17] UNHCR (2019), para 210–11, 217–19; *Yusuf v Canada* (1992).

[18] See discussion in Hathaway and Foster (2014), 169ff, 189; and Crock et al. (2013).

[19] *Ex parte Shah,* 653; *Perampalam v Minister* (1999); *Kovac v Immigration* (1969).

consideration individuals who fall victim to natural disasters, random violence, or general civil conflict who cannot show that they risk being singled out for mistreatment – and that they have no state prepared to offer them assistance.[20] Hathaway and Foster (2014, ch 3) offer human rights law as a mechanism to structure the concept of persecutory harm, capturing a hierarchy ranging from physical assaults threatening life and liberty through to acute social and economic privations.

Again, Article 5(3) of the CRPD invite reflection on the possibility that a person with disabilities may experience harm in a unique way. A person's impairment may render them unable or less able to evade persecutory acts. Physical frailty can also mean that a person's experience of harm is disproportionately severe relative to that of an able-bodied victim.[21] It is broadly accepted that disability can both render an individual more susceptible to (regular) abuse and exploitation[22] and attract harms linked directly to the person's impairments. For example, persons with psychosocial disabilities can face state-sanctioned incarceration and cruel and degrading treatment. The central point is that persecution is a question of fact and degree. A person with disabilities may suffer discrimination. They will not be "refugees" unless the discrimination plays out in harms that impede their ability to subsist (to adopt the language of Australia's *Migration Act* (1958), s 5 J(4)). Abusive treatment can amount to persecution if it produces what UNHCR describes as "consequences of a substantially prejudicial nature."[23] For persons with disabilities, a pervasive problem is in showing the point at which policies of general application (including institutionalization) transition from benign responses to lack of resources to actual persecution.

"For Reasons of" and the Five Convention Grounds

If the word "persecution" does not already imply an element of "singling out," the Convention definition also requires claimants to show that their persecution is linked to one of the five Convention grounds. The phrase "for reasons of" has been interpreted by many states to import an element of intention.[24] Again, this can be problematic for persons with disabilities, particularly where harms are caused by omission rather than by positive acts. For example, a failure to make accommodations for disability can be dismissed as a by-product of poverty and limited resources. This is seen in the Australian tribunal decision *0907687* [2010] RRTA 45 which involved a young child with severe disabilities claiming asylum with respect to Jordan, a country best described as overwhelmed by its burden of

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[20] Ibrahim.

[21] See Tamberlin J comments in *SZBQJ v Minister for Immigration* (2005), para 21.

[22] Handicap International and Save the Children (2011) and Smith-Khan et al. (2015).

[23] UNHCR (2019), para 54.

[24] Hathaway and Foster (2014), 380.

refugees. The child was not successful in claiming that he would be persecuted for reasons of his disability.

This issue of intention carries over into consideration of the Convention grounds. Of course, persons with disabilities can fall into any of the five categories. They can be persecuted because of their nationality, race, or ethnicity. They can be targeted because of their religion or because of their political affiliations (actual or perceived). The interesting question is whether they can be characterized as belonging to a "particular social group." Here the jurisprudence is more helpful, with the Canadian case of *Ward* acknowledging the central importance of shared ("innate" and/or "immutable") characteristics that override or complement shared experiences.[25] Hathaway and Foster (2014 at 452) note that state decision makers have accepted that persons with physical, intellectual, and psychosocial impairments can constitute social groups. So too can individuals with particular conditions (such as dwarfism, albinism, autism) and with chronic illnesses. In fact, asylum seekers with obvious disabilities will often have little difficulty in showing that they belong to a cognizable social group. The problems often lie at the point of demonstrating that their treatment amounts to persecution. It is here that evidence of exceptional treatment – discrimination or outright denial of access to scarce resources – becomes critically important. Although again a question of fact, the prevailing jurisprudence shows that a refugee with disabilities will not be required to show that their suffering is at the hands of state actors. It is enough that a state is unable or unwilling to protect the person, even if they face persecution by private individuals.[26]

The Importance of Process: Disability and Refugee Status Determination

Human rights law generally demands that consideration be given to an individual's lived experience and situation. Article 5(3) of the CRPD mandates "reasonable accommodation," described in CRPD General Comment No 6 (at para 26) to include:

> identifying and removing barriers to enjoying human rights; assessing whether accommodation is legally or practically feasible; assessing whether the accommodation is necessary, appropriate, and suitable to achieve the human rights objective.

The objective ("well-founded") element of the Convention definition of refugee should impute an obligation to ensure that asylum seekers with disabilities are given the benefit of the doubt – and process adjustments – in status determination procedures. In practice, this does not always occur. Kagan (2003 at 368) describes the obligation that a refugee make a *credible* claim as "the single biggest hurdle before applicants beginning the refugee status determination process." There is irony in the

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[25] See, for example, *Tchoukhrova v Gonzales* (2005).

[26] Khawar; Hathaway and Foster (2014), 367.

fact that experiences of persecution can cause physical and psychological disabilities that then impact a person's ability to construct a logical narrative. As Smith Khan explores in ▶ Chap. 88, "Widening the Scope of Non-refoulement? The CRPD and the Protection of Persons with Disabilities in Displacement," asylum seekers with hearing disabilities will often be left to face critical status determination procedures without adequate assistance. Immediate barriers to communication such as lack of language proficiency may be addressed through the provision of an interpreter. However, this will never be adequate without appreciation of intersecting issues such as a claimant's cognitive functioning, psychological factors, cultural understandings including gender and religion and education.[27]

The nondiscrimination obligation enshrined in Art 5 of the CRPD, together with the good faith requirements of treaty law (Kälin, 2000), should make the identification of and accommodation for disabilities a matter of priority for states in refugee proceedings. Disabilities such as blindness and gross motor impairments are easy to identify. Hearing deficits, psychosocial and cognitive impairments can be less obvious and so less amenable to adjustments.[28] Accommodating disability is not about charity, but legal rights. It is also a matter with serious consequences insofar as failure to understand a claimant's story can lead to rejection of a refugee claim, failure to protect and even to expulsion and *refoulement*.

The United Kingdom stands out as an example of good practice as a state where considerable thought has been given to the strategies needed to cater for individuals with particular disabilities.[29] The UK Benchbook acknowledges that all process should start with the applicant who should be afforded the opportunity to explain the nature of their impairments and to make submissions on the adjustments required for the proper hearing of their claim. Multiple disabilities create cross-cutting challenges. While the ideal is to seek out and identify disabilities at the start of a process, experience shows that claimants can often try hard to hide their impairments because of cultural fears of stigmatization (Crock et al., 2020, ch 3.5). For this reason, decision makers need to be prepared to make adjustments when a disability becomes apparent. Following are examples of adjustments that may be appropriate for asylum seekers with specific impairments.

Blindness and vision impairment obviously affect a person's ability to read and absorb written material which will impact capacity to participate in legal processes. Visual and mobility impairments may also affect a person's ability to physically attend hearings in locations that are not immediately accessible. This is particularly the case if attendance involves use of public transport and where buildings are difficult to navigate by reason of layout, steps, and no access to elevators. Individuals with hearing loss and deafness face particular challenges in understanding and participating in proceedings. The result can be frustration and confusion. The deaf and hard of hearing can find their behavior misinterpreted as rudeness, indifference,

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[27] See Byrne (2007), 631.

[28] See Crock et al. (2017), especially ch 4; Crock et al. (2014).

[29] See "Disability Glossary: Impairments and Reasonable Adjustments" in Judicial College, 2018.

or (worse) cognitive deficit. Physical and cognitive impairments, including chronic illness, almost always mean that an individual tires easily, making protracting hearings a challenge. The UK Benchbook recommendations for dealing with each category of impairment frequently include exhortations for short hearing sessions and provision for "time out."

In spite of these examples of good practice, the jurisprudence on legal requirements to make adjustments for asylum seekers with psychosocial disabilities is often disappointing. Unless a person completely lacks capacity to understand the nature and effect of the legal process,[30] many decision makers seem unwilling to accommodate struggling claimants. In the absence of dispositive evidence from medical professionals, Australian Courts have consistently found no legal error in the treatment of asylum seekers with psychosocial impairments either in Australia (*SGLB*) or on Nauru (*ROD122,* 2017 and *TTY167*, 2018). In an unrelated 2021 case, the High Court of Australia overruled a Full Federal Court holding that the Minister for Immigration was legally obliged to consider a noncitizen's capacity to read, understand, and make representations taking into account matters such as literacy, English language ability, mental capacity, and health (*EFX17* [2019] [13], [89] (Greenwood J)). EFX17 was an illiterate refugee from Afghanistan who had a schizophrenic illness arising from his traumatic past and substance abuse (*EFX17* [2019] [6], [109]). The High Court found that the lower Court's approach would "require consideration of the extent of the capacity of a recipient to understand material provided, identification of how limitations could be overcome, and the taking of steps to do so." The High Court found that this would create administrative difficulties in tension with the express terms of the legislation.[31]

COVID-19 and Immigration Detention

As the COVID-19 pandemic spread around the world and lockdowns were implemented, States did not only shut their borders to asylum seekers. For those who had managed to enter countries and to lodge refugee protection claims, lockdowns brought isolation, destitution – and a halt to status determination processing. For refugees with disabilities, the impact was predictably harsh, most particularly for those being held in immigration detention.

Australia's reliance on mandatory detention and its continuing use of offshore processing for asylum seekers arriving by boat without visas makes it an egregious example of bad practice (see generally, Gleeson, 2016). The following summary of the SCIL "COVID-19" submission SCIL (2020) made to the Royal Commission into Violence, Abuse and Neglect and Exploitation of People with Disability (DRC) is

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[30] See discussion of the principle of "Gillick competence" in *Gillick v West Norfolk and Wisbech* (1986); and McSherry (2012).

[31] EFX17 [2021], [28]. It should be noted that the Court found for the applicant, but on a narrow matter of statutory interpretation.

worth quoting at length. Parenthetically, in preparing this submission, SCIL researchers were unable to find publicly available data on the incidence and nature of disabilities in immigration detention (either in Australia or in the offshore processing centers). They note:

> For immigration detainees with physical disabilities,[32] detention settings have fallen short because of barriers to accessibility and mobility that have resulted in neglect and loss of dignity. The use of elevated, demountable buildings accessible only by stairs in regional processing centres are examples in point.[33] Across Australia, detention sites are characterised by poor ventilation and cramped corridors. Prolonged, indefinite detention continues to cause and/or exacerbate psycho-social disabilities. As of 31 May 2020, the average period of time for people held in detention facilities was 553 days. Self-harm and suicides are ongoing (The Age, 2020).
>
> The stigma of disability has been exploited by a system which has continued to discourage disclosure of disabilities and often directly discriminates against detainees with disabilities. Requests for accommodation of disabilities have been met with lacklustre and unsatisfactory responses. In the result, detainees with disability have been unable to live with dignity, independence and autonomy (in breach of CRPD, Arts 19, 5(4) and 14(2)). An asylum seeker of short stature was deliberately selected for processing in Papua New Guinea where he was not even afforded the dignity of an accessible toilet despite multiple requests (Amnesty International, 2016, 55). There are accounts of persons with neuro-developmental disorders denied access to specialist psychiatric services (*MZYYR*). Children with physical disabilities have fallen by the wayside (Multicultural Disability Advocacy Association of NSW, 2014).

Australia's persistence with immigration detention throughout the pandemic was at odds with the approach taken in Britain (The Guardian, 2020), Canada (where around half of detainees in immigration detention were paroled: Global News, 2020), and Belgium where 300 detainees were released when safe social distancing became impossible (DeMorgen, 2020). The US courts released into the care of family and friends immigration detainees suffering from chronic medical conditions including diabetes, asthma, heart disease, post-traumatic stress disorder, and depression (CBS News, 2020). The rationale for release was well summarized by the US District Court judge Bernal in the *Fraihat* class action (*Fraihat*, 5) (Fraihat v United States Immigration, 2020):

> The risk of infectious disease in prisons and jails are significantly higher than outside for several reasons. First, social distancing to prevent the spread of disease by respiratory droplets is often impossible in congregate settings, due to poor ventilation and inadequate space, and jails and prisons often lack access to personal protective equipment like masks, gowns and eye shields. Second, jails and prisons often lack resources for diagnosing and treating infectious disease. Simple segregation or solitary confinement measures as an outbreak management technique tend to backfire; they result in less medical attention and increased chances of death.

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[32] See, e.g., cases where the applicant required a wheelchair: *XTZM and Minister for Immigration* (2020); HLQV; 1,709,735 (2018) (Refugee); EWR18 (2018); *Ahmed* (2017); *AUU15* (2017); *Nguyen v Minister* (2017); N98/26275 (2000).

[33] This occurred at several locations. See, SCIL, articles on detention and COVID-19.

> Isolated detainees quickly experience increased psychological distress that manifests in self-harm and suicidality which requires rapid response and intensive care outside the facility. Unless an individual is held in a negative pressure room, his or her respiratory droplets may still flow outwards to the rest of the facility. Third, people held in jails and prisons are more likely than others to have chronic underlying health conditions that make them susceptible to infectious disease. Finally, new information about COVID-19 suggests it may be transmissible through shared bathrooms and cell toilets without lids.

Durable Solutions: Ending Refugee Status

Where a person is recognized as a refugee, UNHCR groups individuals into three broad categories to indicate how a person is to find a new life going forward. Known as "durable solutions," these are: local integration, resettlement in a third country, and repatriation (where conditions change in a home country so as to allow safe return). Refugees with disabilities face challenges in all three of these scenarios.

It is beyond the scope of this chapter to consider issues around the repatriation of refugees with disabilities (and the cessation of refugee status). The subject is broad and has become increasingly important as more host countries have opted to grant refugees temporary status instead of permanent residence allowing pathways to citizenship. Essays by Atak and Crépeau (2021), Zieck (2021), and Long (2021) go some way towards outlining the many issues facing refugees generally. It is safe to assume that the challenges facing refugees with disabilities are magnified by both impairment, resource constraints, and exclusionary attitudes.

In terms of global experience, most refugees will end up in the country where they first seek asylum. The unhappy reality is that countries hosting the largest numbers of refugees are also the poorest in terms of resources. For persons with disabilities in these countries, life can be very difficult. When the privations of displacement as a refugee are added to the mix, the likelihood of positive outcomes diminishes. Although refugees in developing countries are now beginning to organize (Alio et al., 2020), it is fair to say that advocacy for those living with disabilities remains a work in progress. One barrier to progress that the author observed in her research travels has been lack of connections between local disabled peoples' organizations and refugee groups. An example of good practice was in Uganda where deaf community organizations were making an effort to reach out to refugees in the settlements who were deaf and hard of hearing (Crock et al., 2017, Ch 3). Young refugees with disabilities are at particular risk of being denied access to education, a critical development tool and basic human right (Human Rights Watch, 2018). The other challenge for refugees with disabilities is often access to employment opportunities – and to other aspects of participation in society.

Through its country reviews, the CRPD Committee has engaged with the treatment of refugees with disabilities by host countries. Jordan and Uganda stand out as examples in point. Interestingly, both have had nationals serve on the Committee (although not on the specific reviews!). The Committee rightly commended both states for their generosity and positive approach. However, concerns were raised about the failure to include persons with disabilities in disaster planning (Jordan)[34] and in Peace, Recovery and Development Plans (Uganda).[35] Specific questions about refugees with disabilities were also asked in the country review of Turkey[36] and the United Kingdom.[37] Refugees and asylum seekers did not feature in the Committee's initial observations on Australia.[38] Australia's second and third report were considered in September 2019. Criticisms focused particularly on the situation of refugee and asylum seeking children with disabilities detained in Australia and "offshore." The Committee called for release of the children and "the provision of individualized support and recognize the denial of reasonable accommodation as a form of discrimination."[39]

The role of UNHCR in securing the resettlement of refugees in third countries is a small but important part of global attempts to manage mass displacements. As Kneebone and Macklin (2021) document, the number of refugees selected for relocation each year is tiny relative to the scale of the problem. UNHCR responded to the CRPD by both removing the offensive para 4.4.4 from its Handbook,[40] and issuing a new the Resettlement Assessment Tool that takes much less of a "medical" approach to disability.[41] The United States included disability as a "priority one" factor for identifying refugees in situations of heightened need – at least until then President Trump cancelled the refugee intake.[42] As noted earlier, the COVID-19 pandemic brought what programs there were to a grinding halt. With return to a semblance of normality, it seems that refugees with disabilities now have a place in resettlement programs. If the CRPD has achieved anything, it is to cement disability issues as part of mainstream human rights law and international aid and development.

Cross-References

- ► Disaster and Climate Change-Induced Displacement of Persons with Disabilities: A Human Rights Perspective
- ► Inclusive Processes for Refugees with Disabilities: Improving Communication for Deaf Forced Migrants

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[34] See CRPD Committee, "Concluding Observations on the Initial Report of Jordan," para 24.

[35] See CRPD Committee, "Concluding Observations on the Initial Report of Uganda," paras 21, 60.

[36] See CRPD Committee, "Concluding Observations on the Initial Report of Turkey," paras 38–39.

[37] See CRPD Committee, "Concluding Observations on the Initial Report of the United Kingdom of Great Britain and Northern Ireland," para 30.

[38] See CRPD Committee, "Concluding Observations on the Initial Report of Australia."

[39] See CRPD Committee, "Concluding Observations on the Combined Second and Third Periodic Report of Australia," paras 13–14.

[40] See above footnote 7 and Crock et al. (2017), ch 11.

[41] UNHCR, "Resettlement Assessment Tool: Refugees with Disabilities" (2013). See Mirza (2011).

[42] For a discussion, see Mirza (2010).

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Widening the Scope of Non-refoulement? The CRPD and the Protection of Persons with Disabilities in Displacement

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Stephanie A. Motz

Contents

Abstract

The international non-refoulement jurisprudence concerning persons with disabilities currently risks falling into the trap of the outdated medical model of disability. Particularly, the European Court of Human Rights and also the UN Human Rights Committee and the Committee on the Rights of Persons with Disabilities display an often-exclusive focus on a person's medical needs. This results in a denial of the human rights-based approach and thus of the promise of the Convention on the Rights of Persons with Disabilities ("CRPD") to one of its most vulnerable constituencies, persons with disabilities facing expulsion proceedings. The author argues that the CRPD Committee may be ready for a new approach to refoulement cases, drawing on existing case law from other specialist UN treaty bodies and applying the human rights-based approach.

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Introduction

General Introduction

Persons with disabilities make up between 10 and 30 percent of the population of displaced persons (Crock, 2021, p. 779). As such, they are either internally displaced (▶ Chap. 84, "Disaster and Climate Change-Induced Displacement of Persons with Disabilities: A Human Rights Perspective") or find themselves in a foreign state, in which they may have no right to remain and apply for asylum or become subject to expulsion proceedings. In the context of asylum or expulsion proceedings, the refoulement prohibition as guaranteed in international human rights law is a crucial safeguard in protecting persons with disabilities.

This chapter examines the extent to which the Convention on the Rights of Persons with Disabilities (CRPD) advances obligations concerning the refoulement prohibition for states hosting non-citizens with disabilities who are subject to expulsion proceedings. It explores the recent practice of the CRPD Committee on the refoulement prohibition in cases concerning persons with disabilities and examines the Committee's reliance on principles from international human rights law. In particular, the present chapter analyzes the case law of the European Court of Human Rights (ECtHR) and other UN treaty bodies in the context of refoulement and persons with medical needs, and argues that some of the jurisprudence has not yet effected the necessary shift away from the now generally abandoned medical model to the human rights-based model of disability. It concludes with an analysis of the CRPD's potential with its promise of the human rights approach also for persons with disabilities in expulsion proceedings.

The Refoulement Prohibition in International Human Rights Law

In its broadest sense, the refoulement prohibition protects foreign nationals from being expelled to a country where they face some form of serious harm (Costello & Foster, 2016, p. 284 referring to the "same fundamental core" of all the different refoulement prohibitions). It is enshrined in various international and regional human rights treaties, although its precise scope varies somewhat between the different legal regimes. International extradition treaties and international humanitarian law also contain explicit and implicit refoulement prohibitions (Lauterpacht & Bethlehem, 2003, paras 5–9; Costello & Foster, 2016, p. 283). It has been described as the "cornerstone of the protection of refugees" (Wouters, 2009, pp. 1, 23–24; Kälin et al., 2011, para. 2; Durieux, 2013, p. 248) and provides refugees with the most essential guarantee, the protection from being sent back to a country where they fear persecution (de Weck, 2022, paras 2, 5).

Most notably, Art. 33 of the 1951 Refugee Convention explicitly prohibits the expulsion of refugees to a state where their life or freedom would be threatened. Further express refoulement prohibitions are contained in Art. 3 of the Convention Against Torture (CAT)[1] and Art. 16 of the Convention on Enforced Disappearances (CED).[2] In addition, the refoulement prohibition has been found to flow from the prohibition of torture and other ill-treatment in the International Covenant on Civil and Political Rights (ICCPR),[3] the Convention on the Elimination of Discrimination Against Women (CEDAW),[4] the Convention on the Rights of the Child (CRC),[5] the Convention on the Elimination of Racial Discrimination (CERD),[6] and now also by the Convention on the Rights of Persons with Disabilities (CRPD).[7] Seven of the UN Committees have decided or assessed individual complaints concerning refoulement: the UN Human Rights Committee (HRC),[8] the CAT Committee,[9] the CEDAW Committee,[10] the CRC Committee,[11] the CED Committee,[12] the CERD

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[1] While the express wording of Art. 3 CAT only prohibits the expulsion to a country where the person would face *torture*, the CAT Committee has clarified in its General Comment No. 2 on the Implementation of Article 2 by States parties, 24 January 2008, CAT/C/GC/2, para. 6, and its General Comment No. 4 (2017) on the implementation of article 3 of the Convention in the context of article 22, 4 September 2018, CAT/C/GC/4, para. 16, that the refoulement prohibition also extends to *cruel, inhuman or degrading treatment or punishment* (CIDTP); the CAT Committee thus found a violation of Art. 16 CAT (prohibition of CIDTP) in the refoulement case of *A.N. v. Switzerland*, comm. no. 742/2016, 3 August 2018, paras. 7.3 and 9.

[2] Art. 16 CED prohibits the expulsion to a country where there are substantial grounds for believing that there is a real risk of enforced disappearance.

[3] It flows from Arts. 6 and 7 ICCPR, see, e.g., HRC, General comment no. 31, The nature of the general legal obligation imposed on States Parties to the Covenant, 26 May 2004, CCPR/C/21/Rev.1/Add.13, para. 12.

[4] CEDAW, General Recommendation No. 32 on the gender-related dimensions of refugee status, asylum, nationality, and statelessness of women, 14 November 2014, para. 5.

[5] CRC, General Comment No. 6 (2015) on the Treatment of Unaccompanied and Separated Children outside their Country of Origin, CRC/GC/2005/6, 1 September 2005, paras. 26–28.

[6] CERD, General Recommendation No. 30 on discrimination against non-citizens, 2005, paras. 25 and 27.

[7] See the CRPD Committee's first decision on refoulement in *N.L. v Sweden*, comm. no. 60/2019, 28 August 2020, and the Committee's earlier obiter dicta in *O.O.J. and Ors v. Sweden*, comm. no. 28/2015, 18 August 2017, para. 10.3.

[8] For its first decision see HRC, *Torres v. Finland*, comm. no. 291/1988, 05.04.1990.

[9] See, e.g., above footnote 1.

[10] For the first decision finding a violation of the refoulement prohibition, see CEDAW, *A. v. Denmark,* comm. no. 53/2013, 19 November 2015, and the Committee's early obiter dicta in *M. N.N. v. Denmark*, comm. No. 33/2011, 15 July 2013, paras 8.9–8.10.

[11] For the first decision finding a violation of the refoulement prohibition, see CRC, *I.A.M. (on behalf of K.Y.M.) v Denmark*, comm. no. 3/2016, 25 January 2018.

[12] For the first violation of the refoulement prohibition, see CED, *E.L.A. v. France*, comm. no. 3/2019, 25 September 2020.

Committee,[13] and more recently the CRPD Committee.[14] In addition, the refoulement prohibition is expressly or implicitly contained in regional human rights treaties and for present purposes particularly pertinently in Art. 3 of the European Convention on Human Rights (ECHR).[15]

It was the European Court of Human Rights (ECtHR) in 1989, which decided the first application on non-refoulement under international human rights law. This was the case of *Soering* concerning the famous German fugitive who faced extradition to the United States in order to be tried for the cold-blooded murder, supposedly committed together with his girlfriend, of her parents and who could have faced the inhuman or degrading death row phenomenon there (Soering v United Kingdom, 1989). The Court held, only 5 years after the first express enactment of the refoulement prohibition in Art. 3 CAT, that the refoulement prohibition – prohibiting removal to a state where substantial grounds have been shown that the person would face a real risk of torture or inhuman or degrading treatment – was implicit in the prohibition of torture and inhuman or degrading treatment in Art. 3 ECHR and prevented his removal at that point (Soering v United Kingdom, 1989, para. 91). One year later, the HRC decided its first refoulement case (Torres v Finland, 1990) and another 4 years later, the CAT Committee followed suit (Mutombo v Switzerland, 1994; see further on these developments de Weck, 2016, pp. 3, 40; Schweizerisches Kompetenzzentrum für Menschenrechte (SKMR) & Kälin, 2012, pp. 28–31; Çali et al., 2020, p. 359).

Since then, the UN Committees and the ECtHR are regularly called upon to apply the refoulement prohibition, because they offer a "safety net" – albeit incomplete – to refugees preventing their forcible return to persecution (Lambert, 1999; Durieux, 2013, pp. 249–251; Costello, 2016b, p. 180). The majority of these refoulement cases concern asylum proceedings at the domestic level (Çali et al., 2020, p. 360 considering the decisions of the HRC, CAT, CEDAW, and CRC Committees; for a discussion of the ECtHR's case law, see de Weck, 2016; Costello, 2016a; for a discussion of the CAT, CEDAW, and ECtHR case law, see Motz & de Weck, 2017). The UN Committees effectively fill a void that was left by the first UN treaty concerning international human rights, the 1951 Refugee Convention, for which the drafters at the time did not provide an individual complaints mechanism in contrast to all subsequent UN human rights treaties (Zieck, 2011, pp. 1499, 1508; McAdam, 2011; Chetail, 2021, pp. 212–213; Motz, 2021, pp. 22–25). Today, the ECtHR and the UN Committees play an important role through their individual complaints procedures in shaping the precise contours of the refoulement prohibition in international human rights law (for a discussion of their role in this context, see

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[13] For the first publicly known interim measure that has been granted by the CERD Committee, which the author could find, in a refoulement case, see humanrights.ch, *Renvois: la pratique des autorités migratoires suisses menace les droits humains*, available at: https://www.humanrights.ch/fr/qui-sommes-nous/autorite-migratoires-mesures-conservatoires

[14] See, e.g., above footnote 7.

[15] For an overview of other regional human rights systems and refoulement, see OMCT Handbook Series Vol. 2 (2014) and Vol. 3 (2014); see also Çali et al. (2020), p. 359.

Schürmann & Scheidegger, 2009; Chetail, 2014; de Weck, 2016; Costello, 2016b; Motz & de Weck, 2017; Çali et al., 2020).

Status Quo: The Scope of the Refoulement Prohibition for Persons with Disabilities

In order to examine this more closely, it is necessary to first take a closer look at the ECtHR's jurisprudence in medical cases (section "The ECtHR Non-refoulement Case Law in "Medical Cases"") and the prevalence of the medical approach in its case law (section "The ECtHR's Reliance on the Medical Model in Non-refoulement Cases") before developing a human rights-based approach to refoulement cases of persons with disabilities (section "A New Approach to Non-refoulement of Persons with Disabilities").

The ECtHR Non-refoulement Case Law in "Medical Cases"

The ECtHR is the international forum with the most detailed and long-standing jurisprudence in relation to "medical cases," i.e., cases in which persons suffering from some serious illness or disability have claimed a violation of the refoulement prohibition on account of the lack of medical treatment. Particularly the ECtHR's judgment in *Paposhvili v. Belgium* has greatly influenced the non-refoulement case law of the UN Committees in "medical cases." The Grand Chamber judgment in *Paposhvili* is the product of a line of case law, which will be briefly set out here.

In a string of cases starting with its (in-)famous judgments in *D v. United Kingdom* concerning an applicant with AIDS and *N v. United Kingdom* concerning an applicant with HIV, the ECtHR established a restrictive approach focusing almost entirely on the applicants' need for medical treatment (with a limited consideration of the available social network, though this has not proved decisive in favor of protection in subsequent cases). The Court found a violation of Art. 3 ECHR in the case of *D* because there was no antiretroviral treatment available in St. Kitts and *D* would have faced the "real risk of dying under the most distressing circumstances" and without family support (D. v United Kingdom, 1997, paras 52–54). However, conscious of the financial repercussions of this precedent (N. v. United Kingdom, 2008, para. 44), the Court subsequently backtracked in the case of a Ugandan applicant with HIV in *N* stating that it was only in "very exceptional cases" that the removal of a person with medical needs would entail an Art. 3 ECHR violation (at para. 42). According to the Court, the reason for this was that the harm ensued not from the state or private actors but from a "naturally occurring illness and the lack of sufficient resources to deal with it in the receiving country" (N. v. United Kingdom, 2008, para. 43). The focus in both precedents was on the illness and the availability of medical treatment, with the absence of family members as an additional but not sufficient factor. In neither of these cases did the Court find it apt to consider other aspects, for instance, whether the lack of resource allocation to the treatment of persons with HIV or AIDS in St. Kitts or Uganda had a discriminatory element, specifically targeting this very marginalized group of people (UNAIDS, 2015, 2017).

The same exceptionality threshold has been applied to cases involving mental health issues like schizophrenia, which in the asylum context have all been refused see e.g. (Bensaid v United Kingdom, 2001, paras 16, 37; Tatar v Switzerland, 2015, para. 16). The only exception to the application of the exceptionality threshold is the case of a British national subject to extradition proceedings to the United States on terrorism charges and who had been diagnosed with paranoid schizophrenia. In its first judgment on the matter, the ECtHR found that the extradition of Mr. Aswat to the United States's supermax prison would be in breach of Art. 3 ECHR on account of his mental health, but also stressed that the case was to be distinguished from other expulsion cases (in which the exceptionality threshold applied) as it concerned extradition in a detention setting and the applicant was without family support (Aswat v United Kingdom, 2013, para. 57). However, Mr. Aswat was nonetheless subsequently extradited to the United States on the basis of diplomatic assurances, which the ECtHR approved (Aswat v United Kingdom, 2015, paras 30–31). This was so despite the fact that it was established that the removal of Mr. Aswat from the high-security hospital at which he was detained in the UK to a prison even with considerable mental health facilities would "put the applicant at risk of relapse into an acute psychotic state" (Aswat v United Kingdom, 2013, paras 51, 55; Aswat v United Kingdom, 2015, para. 15). He was subsequently sentenced in the United States to 20 years in prison with specialized psychiatric care, rather than a psychiatric institution as was previously deemed necessary.[16] This case also serves to illustrate the lack of reliability of diplomatic assurances which has been raised particularly in the context of extradition proceedings (de Weck, 2016, pp. 365–366; CAT, 2018, para. 20; Çali et al., 2020, pp. 372–373), but equally pertains in the medical context.

The ECtHR has adapted the refoulement prohibition to new situations, including those involving violations of socioeconomic rights, such as the living conditions of asylum applicants in Greece (M.S.S. v Belgium and Greece, 2011) or the humanitarian conditions in a Somali refugee camp (Sufi and Elmi v United Kingdom, 2011), leading to an interpretation of the refoulement prohibition which addresses present-day challenges of migration law. However, the Court has made it crystal clear that this subsequent case law involving general violations of socioeconomic rights does not apply to removal cases of persons with disabilities. In the case of *S.H.H. v. United Kingdom* concerning an Afghan applicant who had been seriously injured by a rocket launcher in Afghanistan and had had one leg amputated, leaving him in a wheelchair, the Court addressed this question (S.H.H. v United Kingdom, 2013). By four votes to three, it decided that the impossibly high exceptionality threshold from *N. v. United Kingdom* rather than the normal test under *M.S.S.* and *Sufi and Elmi* concerning living conditions applied. As a result of the high threshold, there was no

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[16] Reuters, the UK man gets 20 years in the US prison over Oregon militant camp, 16 October 2015, available at: https://www.reuters.com/article/us-usa-security-aswat-idUKKCN0SA18K20151016

breach of Art. 3 ECHR in the case of the disabled applicant's removal to Kabul (S.H.H. v United Kingdom, 2013, paras 89–93). The majority of the Court accepted that there was widespread discrimination of persons with disabilities in Afghanistan but held that this did not lead to a different result (at para. 94). The minority of three dissenting judges, however, called for a disability-sensitive interpretation of Art. 3 ECHR (joint dissenting opinion of Judges Ziemele, David Thór Björgvinsson and De Gaetano, para. 4). The division of the Court on these matters persisted over some years, with seven out of eight judges filing concurring opinions on this matter in a case concerning a Cameroonian HIV positive applicant who faced an 98 percent chance of not being able to access antiretroviral treatment upon return and whose application was equally refused (Yoh-Ekale Mwanje v Belgium, 2011).

At the time, it was hoped that the Court would seize the opportunity of the next medical case in order to review its controversial case law and adopt a more disability-sensitive interpretation of Art. 3 ECHR (see also the dissenting opinion of Judge Pinto de Albuquerque in S.J. v Belgium (formerly known as Josef v Belgium*)*, 2014 concerning the strike out of this case of an HIV positive single mother, which would have provided an opportunity for the Court to review its case law in medical cases; on all of this, see also Motz, 2015, pp. 186–192, and Costello, 2016b, pp. 189–191).

However, the Grand Chamber's eventual review of its case law in *Paposhvili v. Belgium* proved underwhelming. The case concerned an applicant who had already died of his illness at the time of the Court's judgment (Paposhvili v. Belgium, 2016, paras 1, 10). In that case, the Grand Chamber held that "other very exceptional circumstances" may also give rise to a breach of Art. 3 ECHR, where "substantial grounds have been shown for believing that he or she, although not at imminent risk of dying, would face a real risk, on account of the absence of appropriate treatment in the receiving country or the lack of access to such treatment, of being exposed to a serious, rapid and irreversible decline in his or her state of health resulting in intense suffering or to a significant reduction in life expectancy" (Paposhvili v. Belgium, 2016, para. 183). While the Court stated that the test was now somewhat relaxed, it remains a high threshold (ECtHR, 2017, pp. 59–60 per Guido Raimondi).

Indeed, it is striking that the only two applications involving removals of persons with disabilities and medical needs, which the Court has granted, concerned one dead person in *Paposhvili* and one on his deathbed in *D v United Kingdom*. Furthermore, the hope that the judgment in *Paposhvili* would actually lower the threshold for medical cases (Çali et al., 2020, p. 382) has since been shattered. In December 2021, the Grand Chamber reached its judgment in *Savran v Denmark*, in which the Court reversed the Chamber finding of a violation of Art. 3 ECHR in the case of the removal of an applicant suffering from schizophrenia to Turkey without assurances for adequate medical treatment. The Court reiterated the relevant principles from *Paposhvili* and made it clear that Art. 3 ECHR is only applicable at all, when a "serious, rapid and irreversible decline" in the applicant's health would ensue in case of removal (Savran v Denmark, 2021, paras 130, 133, 134). On the facts, the Court found that schizophrenia was not a sufficiently serious illness to bring the applicant within the *Paposhvili* threshold of Art. 3 ECHR so that Art. 3 was not applicable at all (Savran v Denmark, 2021, para. 141). This was so despite the fact that in the absence of treatment, the psychotic symptoms would worsen, leading to a significantly higher risk of committing offences against the person and aggressive behavior. In the Court's view, this did not constitute the necessary "intense suffering" required for Art. 3 ECHR to be applicable (Savran v Denmark, 2021, paras 143–144 but see the partly dissenting partly concurring opinion of Judge Serghides on this point at paras 13–15).

The *Paposhvili* judgment has been criticized for failing to follow the ECtHR's own principles concerning refoulement (Bianku, 2021, p. 103). More generally, the Court has been criticized for its unprincipled approach on equality issues in the context of migration cases (Moreno-Lax, 2021, p. 59). Indeed, the Court's reluctance to protect persons with disabilities from expulsion blends in with its slow recognition of disability rights in general (Zimmermann, 2022, p. 183). While the Court sometimes resorts to the concept of vulnerability in order to address such equality issues and this has served applicants with disabilities on rare occasions,[17] the designation of persons with disabilities as vulnerable instead of a contextual, whole-of-person approach, which would allow the identification of circumstances that could render anyone vulnerable, has been criticized (Moreno-Lax, 2021, p. 59; Zimmermann, 2022, p. 322).

Strasbourg's approach to refoulement cases has generally been criticized and the Court has been reminded to focus its mind "first towards 'protection' of an absolute right" in Art. 3 ECHR (Bianku, 2021, p. 103; Dembour, 2021). While it appears that the Court has adopted this restrictive stance out of fear of becoming an asylum court or a "fourth instance" in the midst of a migration crisis in Europe, the hostile political climate would be a time when the Court's role as the guardian of indispensable guarantees is paramount (Çali et al., 2020, pp. 381–382; Bianku, 2021, p. 98; Dembour, 2021).

Critical Appraisal of the ECtHR's Approach based on Disability Rights

The ECtHR case law in the medical cases can be criticized for a further reason, namely the Court's reliance – in all but name – on the medical model of disability. According to the medical model of disability, the focus is on the (mainly medical) consequences of the impairment and their cure or removal with the aim of ridding persons with disabilities of their impairments and approximating them to the non-disabled norm as far as possible (Kanter, 2006, p. 291; Lawson, 2006, p. 572). The Court's case law, since *D v. UK* and up until and including the recent judgment in

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[17] See the migration cases decided not in an asylum context in *Kiyutin v Russia,* app. no. 2700/10, 10 March 2011, para. 63, *Novruk and Ors v. Russia,* app nos 31039/11, 48511/11, 76810/12, 14618/13, and 13817/14, 15 March 2016, paras. 86–88, or *Renolde v. France,* app. no. 5608/05, 16 October 2008, para. 84, Nasri v France, app no 19465/92, 13 July 1995.

Savran v. Denmark, focuses exclusively on the seriousness of the medical condition and the availability of medical treatment as threshold questions for Art. 3 ECHR to apply. And while the existence of family members and a social network has also been referenced by the ECtHR as pertinent, it appears from the jurisprudence that this has only ever been used to refuse cases and this on doubtful grounds (Blöndal & Mjöll Arnardóttir, 2018, p. 159). While the Court's litmus test in *N v UK* meant that domestic courts only granted protection to persons who were "close to death" (ECtHR, 2017, p. 60 per Guido Raimondi), the subsequent developments in *Paposhvili* and *Savran* can now hardly be said to lower the bar for protection. In addition, through the ECtHR's express refusal to apply its general case law on socioeconomic rights and living conditions to persons with medical needs (see *S.H.H.* above), the Court relies in all cases concerning persons with disabilities – even those who do not specifically depend on medical treatment as the wheelchair user in *S.H.H.* – on an exclusively medical model. This is no longer in line with international human rights law, as has also been pointed out by various dissenting judges over time.

In particular, this approach to the refoulement of persons with disabilities is incompatible with the CRPD. For the CRPD heralds, a paradigm shifts away from the previously prevalent medical model to the human rights-based approach to disability. The human rights-based model views persons with disabilities as rights holders and members of our society who are more hindered by the "physical and attitudinal barriers societies erect to exclude and stigmatize them" than by their own impairment (Kanter, 2006, p. 291; Lawson, 2006 and see also Art. 1 CRPD). The human rights approach is expressed most clearly in Art. 1 CRPD which emphasizes that a disability consists of the interaction of an impairment with various barriers that hinder the person's full and effective participation in society on an equal basis with others (Kanter, 2006, p. 291) (see ► Chap. 87, "Disability and Refugee Protection"). The CRPD moves international human rights law from a concept of formal equality to a concept of multidimensional equality (Mjöll Arnardóttir, 2009, p. 41). The focus no longer rests merely on the impairment. Instead, the various barriers which society erects and which prevent the person's full and equal participation in society are recognized as a key factor rendering a person disabled. The CRPD's aim is to protect persons with disabilities not as objects of charity or simply as persons in need of medical treatment but as human beings on an equal footing with others and as rights-holders whose dignity must be respected in every way (Flóvenz, 2009, p. 259; MacKay, 2007, p. 328; Mjöll Arnardóttir, 2009, p. 41; Quinn & Degener, 2002). The fact that all Council of Europe Member States have either signed or ratified the CRPD[18] supports the argument that these rights should now be relevant also in expulsion cases under the ECHR (see also Art. 53 ECHR).

An approach to refoulement cases, which adequately reflects the human rights approach to disability would not focus exclusively on the applicant's medical needs.

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[18] In fact, Lichtenstein is the only Council of Europe member state which has not yet ratified the CRPD.

Rather, it would take a wholistic view of the situation the person would face in the destination state and evaluate the extent to which their human rights would be protected and whether they would face discrimination or human rights violations amounting to serious harm.

The CRPD Committee on Non-Refoulement

The CRPD does not contain any explicit reference to the refoulement prohibition or to refugees with disabilities. However, the CRPD Committee has variously protected the rights of refugees with disabilities, particularly in the context of Art. 11 CRPD on situations of risk (Motz, 2018, pp. 334–336). In this context, the Committee has addressed the need to adapt asylum procedures and reception conditions in a disability-sensitive manner both in its General Comments and in its concluding observations on state reports.[19]

The CRPD Committee has considered the refoulement prohibition under the CRPD in a line of individual communications concerning Sweden. The Committee's first decision in a refoulement case was taken in August 2017 (O.O.J. and Others v. Sweden, 2017). The complaint concerned a Nigerian asylum-seeking family with a child who had been diagnosed with autism and further psychosocial disabilities. The child's impairments had not been considered in the asylum proceedings but in separate migration proceedings, in which the Swedish authorities had refused the family's application. The family applied to the CRPD Committee arguing that the removal of their son to Nigeria would breach Arts. 7, 15(2), 24, 25, 26, and 28 CRPD in addition to a procedural violation of Art. 12 CRPD. In particular, they argued that there were no autism-specific education, health care or habilitation and rehabilitation services, no appropriate and affordable services and support in general for their son's disability needs in Nigeria, and that the whole family would be excluded from Nigerian society because of their son's disability (O.O.J. and Others v. Sweden, 2017, para. 3). While the CRPD Committee declared the case inadmissible, because the family no longer faced expulsion, it nevertheless seized the opportunity to reject Sweden's argument that the CRPD was not applicable to expulsion cases in general. Significantly, the Committee stressed that "the removal by a State party of an individual to a jurisdiction where he or she would risk facing violations of the Convention may, under certain circumstances, engage the responsibility of the removing State under the Convention which has no territorial restriction clause" (O.O.J. and Others v. Sweden, 2017, para. 10.3). The CRPD Committee in *O.O.J.* thus deliberately left open, which CRPD violations would engage the refoulement prohibition and did not limit its *obiter dicta* to particularly serious violations or only

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[19] CRPD, General Recommendation No. 6 (2018) on equality and nondiscrimination, CRPD/C/GC/6, 26. April 2018, para. 44, and see, e.g., Concluding Observations on Greece, CRPD/C/GRC/CO/1, 29 October 2019, paras 15–16; Concluding Observations on Sudan, CRPD/C/SDN/CO/1, 10 April 2018, para. 21(b); and Concluding Observations on Luxembourg, CRPD/C/LUX/CO/1, 10 October 2017, paras 22–23.

the right to life and the prohibition of torture and cruel, inhuman or degrading treatment in Art. 15 CRPD.

However, after this initial protective stance, the Committee's decisions have become more cautious. Its second decision in a refoulement case concerned an Iraqi asylum seeking woman, who had been diagnosed with depression with psychotic features (N.L. v. Sweden, 2020). In Sweden, she had twice been committed to a psychiatric institution after experiencing hallucinations and suicidal ideation. She had raised her medical issues in migration proceedings after the refusal of her asylum claim. The Swedish authorities had refused her a right of stay, because the medical issues were not serious or life-threatening enough. Before the CRPD Committee, she only raised the right to life and the prohibition of torture or cruel, inhuman or degrading treatment (Arts. 10 and 15 CRPD). Sweden argued that its authorities had conducted a thorough examination of the claims and that there was no reason to conclude that their findings were inadequate.

In *N.L. v. Sweden*, the CRPD Committee confirmed its ruling in *O.O.J.*, but slightly adjusted it by introducing the qualifier that only "serious violations of Convention rights amounting to a real risk of irreparable harm" could, under certain circumstances, prevent the complainant's removal (a language borrowed from the HRC)[20]. It also confirmed its ruling in *O.O.J.* that the refoulement prohibition was not limited to violations of the right to life and of the prohibition of torture Arts. 10 and 15 CRPD (at para. 6.4). It further clarified, relying on the HRC's approach to the refoulement prohibition, that it would give considerable deference to national authority's assessments (at para. 7.3). Further, it referred to the HRC decision in *Abdilafir Abubakar Ali and Mayul Ali Mohamad v. Denmark*, finding that the access to medical care was pertinent to the individualized risk assessment of the personal and foreseeable risk a person would face (Abdilafir Abubakar Ali and Mayul Ali Mohamad v. Denmark, 2016). The CRPD Committee also referred to the CAT decision in *Adam Harun v Switzerland* that due account had to be taken of the complainant's health status under the refoulement prohibition in Art. 3 CAT (Adam Harun v Switzerland, 2018). Finally, the CRPD Committee referenced the ECtHR's judgment in *Paposhvili v. Belgium* in detail (at para. 7.5) (Paposhvili v. Belgium, 2016). It held that it had to determine "whether there are substantial grounds for believing that the author would face a real risk of irreparable harm" if removed to Iraq. Given the undisputed diagnoses of the author, which included the risk of severe or life-threatening complications, the fact that the treatment was described as essential and the risk of relapse to be grave without adequate care, the Committee concluded that the Swedish authorities had violated Art. 15 CRPD by failing to assess whether she would in fact be able to access adequate care in Iraq (N.L. v. Sweden, 2020, para. 7.8). As a result of this finding, the Committee did not find it necessary to consider the right to life under Art. 10 CRPD separately (at para. 7.9).

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[20] See e.g. HRC, General Comment No. 31, supra footnote 3, para. 12.

A similar ruling followed in September 2021 concerning an Afghan man diagnosed initially with post-traumatic stress disorder with psychotic features and committed once to psychiatric care because of hallucinations and suicidal ideation (Z.H. v. Sweden, 2021). The medical evidence was again raised in migration proceedings, but the Swedish authorities found that some sort of psychiatric treatment would be available in Kabul so that the complainant could be returned there. Subsequently he was diagnosed with paranoid schizophrenia and the Complainant commenced new proceedings, but the Swedish authorities confirmed their earlier ruling that he could be removed to Kabul. The complainant first applied to the ECtHR, but the Court rejected his claim as inadmissible in a single-judge formation, also refusing the application for an interim measure preventing the complainant's removal (at para. 2.6). He then applied to the CRPD Committee invoking breaches of Arts. 10 and 15 CRPD in case of his removal to Afghanistan as well as violations of Arts. 12 and 13 CRPD (the rights to equal recognition before the law and access to justice) because of the Swedish authorities' failure to provide him with adjustments for his mental health needs in the procedure. Once again, the CRPD Committee qualified its ruling in *O.O.J.* limiting it as in *N.L.* to *serious* violations of Convention rights leading to a risk of *irreparable harm*, including but not limited to Arts. 10 and 15 CRPD (at para. 9.4). The complaints concerning Arts. 12 and 13 CRPD were inadmissible for failure of substantiation (at para. 9.5). The Committee made reference to the HRC, CAT, and ECtHR jurisprudence already relied on in *N.L. v. Sweden* and held that the question therefore was whether upon the complainant's removal to Afghanistan, he would face a real risk of irreparable harm under Arts. 10 and 15 CRPD, "such as being exposed to a serious, rapid and irreversible decline in his health resulting in intense suffering or to a significant reduction in life expectancy" (at para. 10.7).

The Committee also reiterated that it was generally for the domestic authorities to evaluate facts and evidence, unless this is found to be "clearly arbitrary" or amounting "to a denial of justice" (at para. 10.8). Nevertheless, the Committee concluded that the complainant had discharged the burden of proving that there were substantial grounds for believing that he would be exposed to a real risk of ill-treatment upon removal to Afghanistan, while the Swedish authorities had failed to dispel the doubts about that risk. The Committee examined the general reports on the situation of health care in Afghanistan and reached the opposite conclusion from the Swedish authorities: the reports revealed "the limited availability of psychiatric care and access to medication" and a lack of trained professionals, infrastructure, and awareness about mental health issues with very limited resources covering a population of more than 30 million people. In contrast to the Swedish authorities, the Committee concluded therefrom that these deficiencies casted serious doubt on the availability of the health care needed by the complainant in order to prevent a violation of Art. 15 CRPD (at para. 10.9). The Committee added that individual assurances would have been "particularly important" given that the complainant had left Afghanistan at the age of 13 years and would face particular challenges in accessing health care (at para. 10.9). Given the accepted diagnosis of PTSD and the apparently undisputed diagnosis of paranoid schizophrenia, the Committee concluded on a finding of a violation of Art. 15 CRPD and did not consider it necessary to consider Art. 10 CRPD separately.

The CRPD Committee has so far decided one further application of an asylum applicant concerning an Afghan Hazara man who was missing three fingers on his right hand (M.Y. v. Sweden, 2021). The combination of this impairment with his ethnicity as a Hazara and the fact that he had been born out of wedlock had led to a life of exploitation and abuse, including rape. However, while confirming its ruling in *N.L. v. Sweden* (at para. 6.4) the Committee held that the complaint was inadmissible, as his claim that he was mistreated on the basis of his disability was vague and unsubstantiated (at paras. 6.5–6.6). While the Committee may have adopted a somewhat restrictive stance on disability as a contributing factor for serious harm, it is difficult based on the facts and the complaint as set out in this decision, to assess whether the link to disability had been sufficiently substantiated.

The development of the CRPD Committee's early case law concerning the refoulement prohibition displays a strong reliance on highly controversial jurisprudence in cases involving medical needs from other international human rights bodies. It is understandable that the Committee would reference refoulement case law concerning persons with disabilities, as there is otherwise a lack of appropriate guidance on such questions in international human rights law. Yet, as will be argued below, the danger of following the preexisting approach to these so-called "medical cases," particularly of the ECtHR and the HRC, is that the CRPD Committee adopts the medical model of disability in refoulement cases, and thereby deprives some of the most vulnerable persons with disabilities – those facing expulsion – of the promise of the CRPD's human rights approach set out above.

A New Approach to Non-refoulement of Persons with Disabilities

Before elaborating in more detail what a human rights approach to non-refoulement of persons with disabilities would require, it is instructive to consult the practice of other specialist UN Committees. For the practice of the UN treaty bodies has been commended as providing a more principled and sound approach to refoulement in such cases (Çali et al., 2021, p. 15).

The Practice of Other UN Committees

Several of the specialist UN Committees have in individual cases demonstrated that they are more qualified to provide a specialized interpretation of the refoulement prohibition in the area of their core competence than the generalist civil and political rights court, the ECtHR. In particular, the CAT and the CRC Committees have been described as vanguard when it comes to refoulement cases (Çali et al., 2020, p. 381).[21] Their decisions serve as good examples as to how UN Committees can act as the guardian of the rights of the particular group of persons or in relation to the particular issue entrusted to them.

For instance, concerning the right to rehabilitation of torture victims, the specialist body for issues surrounding torture, the CAT Committee, has in two decisions set out an entirely different approach from the ECtHR's medical cases. In its decisions in *A.N. v. Switzerland* and *Adam Harun v. Switzerland*, the Committee considered the lawfulness of the removal from Switzerland to Italy of an Eritrean and an Ethiopian torture victim respectively, who both required urgent medical treatment for their rehabilitation from torture (A.N. v. Switzerland, 2018; Adam Harun v Switzerland, 2018). As opposed to the ECtHR, which requires "intense suffering" before its refoulement prohibition even comes into play, the threshold for the applicability of Art. 3 CAT was crossed by virtue of the fact that the complaints concerned torture survivors with rights under CAT. In addition, the Committee did not exclusively focus on the need for medical treatment, but took a more comprehensive view of the right to rehabilitation services and an environment, in which rehabilitation from torture would be possible (Art. 14 CAT). In *A.N.,* the Committee found that the removal of the applicant to Italy without individual assurances that he would have immediate and long-term access to rehabilitation services constituted a violation of the right to rehabilitation of torture survivors in Art. 14 CAT, of the prohibition of cruel, inhuman and degrading treatment in Art. 16 CAT and of the refoulement prohibition in Art. 3 CAT. In *Harun*, the Committee negated the reliability of individual assurances, as the applicant had already once been removed from Norway to Italy and Italy had at that point assured that he would receive access to the desperately needed medical treatment, which transpired to be untrue. This decision serves as a timely reminder of the lack of reliability of such assurances also in the medical context (at paras 2.6, 9.10–9.11). In this case, the Committee found a violation of the refoulement prohibition in Art. 3 CAT in the case of the complainant's removal to Italy because of the lack of access to rehabilitation services, to accommodation, and to the necessary support measures (at paras 9.8, 9.11). These judgments contrast with an earlier ECtHR judgment in the case of a Syrian torture victim also in desperate need of rehabilitation services and medical treatment, also facing removal from Switzerland to Italy, in whose case, the Strasbourg Court applying its exceptionality threshold in medical cases found no breach of Art. 3 ECHR (A.S. v. Switzerland, 2015). At least when torture survivors with mental

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[21] Other Committees have also proven to be protective of their areas of expertise in refoulement cases, for the CED, see *E.L.A. v. France*, comm. no. 3/2019, 25 September 2020, and even the CEDAW Committee, which has rightly been criticized for its inability to establish "much of a voice on the asylum claims of vulnerable women" (Çali et al., 2020, p. 369; Hodson, 2014, p. 572), has nevertheless demonstrated a more gender-specific interpretation of the refoulement prohibition, e.g., when it comes to private actor persecution, see *A. v. Denmark*, comm. no. XXX; or *R.S.A.A. v. Denmark*, comm. no. XXXX.

health issues resulting from torture are concerned, the CAT therefore appears to offer greater refoulement protection than the ECtHR (Çali et al., 2020, p. 382).

A further example of such a specialist interpretation of the refoulement prohibition can be found in the jurisprudence of the CRC Committee. In addition to the prohibition of torture and cruel, inhuman or degrading treatment, the Committee has extensively relied on the duty to give primary consideration to the best interests of the child pursuant to Art. 3 CRC, finding violations in several expulsion cases so far (A.B. v. Finland, 2021; A.M. (on behalf of M.K.A.H.) v. Switzerland, 2021; I.A.M. (on behalf of K.Y.M.) v. Denmark, 2018; R.H.M. v. Denmark, 2021; V.A. (on behalf of E.A. and U.A.) v. Switzerland, 2020; W.M.C. v. Denmark, 2020). The CRC Committee has also made it clear that the best interests of the child override the general interests in migration control ("Joint General Comment No. 3 (2017) of the Committee on the Protection of the Rights of All Migrant Workers and Members of Their Families and No. 22 (2017) of the Committee on the Rights of the Child on the General Principles Regarding the Human Rights of Children in the Context of International Migration," 2017, para. 33). As a result, the best interests principle has been described as an "autonomous concept that may significantly limit domestic authorities' leeway" (Çali et al., 2020, p. 378).

Concerning refoulement cases of children with medical needs, the CRC Committee has equally refused to follow the ECtHR's restrictive approach in medical cases and has instead held in a case concerning a Sri Lankan family with a baby diagnosed with congenital hypothyroidism that the test was whether medical treatment which is "essential for the life and proper development of the child" is available and accessible in the destination state (D.R. v. Switzerland, 2021, para. 11.6). On the basis that there was extensive published research in Sri Lanka on this disease and that its treatment was "simple, inexpensive and available in the public and private health systems," the Committee found no violation of the refoulement prohibition in this case (at para. 11.6). It is noteworthy, however, that in addition to the invoked Art. 3 CRC, the Committee decided of its own initiative to consider this refoulement case not only under the prohibition of torture or cruel, inhuman or degrading treatment (Art. 37(a) CRC), but also under the right to the maximum extent possible of the survival and development of the child (Art. 6(2) CRC) and the right to the highest attainable standard of health (Art. 24 CRC) (see paras 10.6, 11.6).[22]

The CRC Committee's willingness to provide a wholistic examination in refoulement cases of children can also be gleaned from its recent decision in *A.M. v. Switzerland* concerning the removal of a single mother and her child to Bulgaria. In particular, the Committee took due account of both the mother's mental illness and the fact that the child had suffered trauma as a victim of armed conflict (A.M. (on behalf of M.K.A.H.) v. Switzerland, 2021, para. 10.7–10.8). It considered the destabilizing impact their removal would have on the mother's mental health,

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[22] See also the recent CRC decision in *K.S. and M.S. v. Switzerland*, comm. no. 74/2019, 10.02.2022, para. 7.6, finding a violation of the right to health in Art. 24 taken with Arts. 3 and 6 CRC.

who, for financial reasons, would not have access to medical treatment in Bulgaria, and the fact that the child had not been able to receive services and treatment necessary for his recovery in the past in Bulgaria. Consequently and because of the dire living conditions and the lack of education for the child, the Committee concluded upon a violation of Arts. 6(2), 22, 27, 28, 37, and 39 CRC in case of their removal (A.M. (on behalf of M.K.A.H.) v. Switzerland, 2021, para. 10.8; see also the grant of an interim measure in the case of an Angolan child with a pervasive developmental disorder who required specialist treatment and education, which would not have been available and accessible in Angola in J.G. v. Switzerland, 2019 struck out of the list after grant of a residence permit).

In a ground-breaking admissibility decision, the CRC Committee further accepted that children could claim victim status for the exacerbation or instigation of a child's illness or disability by different states' failures to mitigate the effects of climate change and actually perpetuating its effects (Sacchi and Ors v. Argentina, Brazil, France, Germany and Turkey, 2021, declaring the applications inadmissible for lack of exhaustion of domestic remedies; see also on the issue of climate change Teitiota v. New Zealand, 2019; discussed in Çali et al., 2020, p. 368).

It is worth mentioning that the HRC, which is not specialized as the other Committees but also a generalist civil and political human rights body, has generally followed the ECtHR's approach to medical cases applying an exceptionality threshold (Çali et al., 2020, p. 382). However, it has granted applications in medical cases more often than its European counterpart (Z. v. Australia, 2014; A.H.G. v. Canada, 2015; Jasin v. Denmark, 2015; R.A.A. and Z.M. v. Denmark, 2016; Abdilafir Abubakar Ali and Mayul Ali Mohamad v. Denmark, 2016; Rezaifar v. Denmark, 2017; Y.A.A. and F.H.M. v. Denmark, 2017). Nevertheless, by applying the exceptionality threshold, the HRC takes a different approach from its more specialized counterparts when it comes to the protection of persons with disabilities or medical needs.

In sum, the specialist UN Committees have demonstrated that they act as guardians of particular groups – for instance, of children or of victims of torture and their rights – and that they can step up to the task or providing adequate protection in the area of their core competence also in the context of the refoulement prohibition.

The Role of the CRPD Committee

The CRPD Committee has started to develop its own practice in relation to the refoulement of persons with disabilities and has in some decisions demonstrated that it is ready to be the guardian of the human rights of persons with disabilities also in expulsion settings. In *O.O.J. v. Sweden*, for instance, the CRPD Committee set out a test which was fully in line with the human rights approach by stating that all CRPD violations could, under certain circumstances, prohibit the removal of a person with disabilities. This general statement is in line with the human rights-based approach to disability, which does not reduce the impact of an impairment to its medical implications, acknowledging instead the various barriers which exist in today's societies for persons with disabilities.

Also noteworthy is the Committee's lack of deference in *Z.H. v. Sweden*, in which it demonstrated that it would provide national authorities with limited leeway for doubtful evidentiary assessments. In this sense, the CRPD Committee is already following in the footsteps of its more experienced counterparts, such as the CRC Committee, which has been commended for not following a doctrine of deference at the moment, possibly because of the "significant deficiencies it finds in the countries it has cases from" (Çali et al., 2020, p. 382). A comparable extent of deficiencies likely pertains in the context of many refoulement cases of persons with disabilities.

However, there are some tendencies in the CRPD Committee's decisions in *N.L. v. Sweden* and *Z.H. v. Sweden*, which may lead the Committee to fall into the trap of the ECtHR's case law on "medical cases," following not only a prohibitively restrictive approach with its "exceptionality threshold" but also a line of case law which is based on the medical model. Instead of continuing to follow the ECtHR's approach in these "medical cases," the CRPD Committee may develop its own approach which is compatible with the general protections of the CRPD, justifying limited deference at present.

First, it is suggested here that the CRPD Committee may draw inspiration from the CRC and CAT Committees concerning complainants with medical needs. For instance, the CRC Committee has set out in *D.R. v. Switzerland* that it will examine whether the medical treatment which is "essential for the life and proper development of the child" is available, thereby rejecting the "intense suffering" and "rapid and irreversible decline in health" tests from *Paposhvili* and *Savran*. Similarly, the CAT Committee considered it pertinent in *A.N.* and *Harun* whether the complainants would have immediate and lasting access to the required medical treatment and would find themselves in living conditions which were conducive to the rehabilitation from torture, thereby taking a more holistic view of the complainants' situation in the destination country.

Secondly, if the human rights approach to disability is to be implemented also for persons with disabilities facing removal, an interpretation of the refoulement prohibition as including various CRPD-rights violations is necessary. The CRPD Committee may go back to its original statement in *O.O.J.* that in fact many violations of CRPD rights may amount to serious harm and therefore act as a bar to removal in expulsion cases. In this regard, the Committee may draw inspiration again from the CRC and CAT Committees, who have already relied on rights other than just the refoulement prohibition (in Art. 3 CAT and Art. 37(a) CRC), such as the right to rehabilitation (in Art. 14 CAT) or appropriate measures to promote physical and psychological recovery and social reintegration (Art. 39 CRC), the right to appropriate protection and humanitarian assistance (Art. 22 CRC), the right to an adequate standard of living (Art. 27 CRC) and to education (Art. 28 CRC), or the right to have the best interests of the child taken into account as a primary consideration, the child's right to survival and development or the highest attainable standard of health (in Arts. 3, 6 and 24 CRC). As the guardian of the human rights of persons with disabilities, the CRPD Committee is tasked with their protection from disability discrimination in expulsion settings. While it is generally accepted in international human rights law that nonnationals can be treated less favorably, a more in-depth scrutiny is required when the differential treatment results in discrimination (Vandenhole, 2014, p. 218). There is also an acute concern about the links between racism and migration (Vandenhole, 2014, p. 218). Given that discriminatory attitudes towards persons with disabilities persist in many countries around the world, a particularly rigorous scrutiny will be required in the context of expulsion cases. Several violations of the CRPD have the potential of seriously affecting a person's life to the extent that it causes them serious harm, such as violations of the right to liberty and security of the person in Art. 14 CRPD which has been described as "one of the most precious rights to which everyone is entitled" (CRPD, 2016, para. 3) and of the corresponding right to live independently and be included in the community in Art. 19 CRPD (CRPD, 2016, para. 9). Equally, violations of the freedom from exploitation, violence, and abuse, and the right to respect for physical and moral integrity and security, e.g., through forced treatment, in Arts. 16 and 17 CRPD as well as in the case of female applicants Art. 6, will regularly amount to serious harm. Children may experience serious harm through the denial of their rights to access to education and child- and disability-specific living conditions in Arts. 24, 28, and 7 CRPD and an adult may face serious harm on account of violations of the rights of access to employment, accessibility, and personal mobility in Arts. 27, 20, and 9 CRPD (see in detail on all of this Motz, 2021, Chap. III). In its examination of communications, the Committee may also find it appropriate to examine additional rights *proprio motu*, as the CRC Committee has for instance done with the rights concerning survival, development and health (under Arts. 6 and 24 CRC, see *D.R. v. Switzerland*, paras 10.6, 11.6).

While there may be an issue of fragmentation if the Committee departs from the ECtHR's approach (Çali et al., 2020, p. 357),[23] other UN Committees have not been stopped by this risk from undertaking a thorough and rights-based assessment in specific refoulement cases.[24] An example of this is the CRC Committee's decision in *D.D. v. Spain* concerning the removal of a minor from the Spanish border in Melilla to neighbouring Morocco (D.D. v. Spain, 2019). The Committee here reached the opposite conclusion from the previous judgment of the ECtHR in *N.D. and N.T. v. Spain*, concerning adults who tried to cross the same border and were sent back, and found violations of Arts. 3 and 37 CRC. The ECtHR decided quite differently, finding the case concerning refoulement under Art. 3 ECHR inadmissible and only communicating the issues relating to the collective expulsion under Art. 4 Protocol 4 to the government, and then finding no violation in relation to that either (see N.D. and N.T. v. Spain, 2020, paras 3–4 on the noncommunication of the

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[23] Çali et al. (2020), p. 357.

[24] Compare the CRC Committee's ruling in *D.D. v. Spain* with the ECtHR's ruling in ND and NT v Spain a few months prior – the CRC Committee stepped up to its tasked and reached the opposite conclusion from the ECtHR based on the CRC-specific guarantees for children.

refoulement aspect). While the CRC Committee's position on this has been described as vanguard on extraterritoriality by stating that border guards have a duty to protect children at their borders (Çali et al., 2020, pp. 381–382), the ECtHR's assessment has been criticized as "cursory" and the lack of a finding of violation as inconsistent with the Court's own case law (Moreno-Lax, 2021, pp. 50, 52). These potentially conflicting assessments, however, enrich the human rights dialogue which already exists in a "polycentric legal system" such as that of international human rights law (Zimmermann, 2022, p. 439).

It is important that the CRPD Committee, as the specialist body entrusted with disability rights at the UN level, steps up its efforts as the guardian of the human rights of persons with disabilities also for those in need of international protection.

Conclusion

The examination of the existing case law at an international level has demonstrated that the scope of the refoulement prohibition has not been markedly widened by the practice of the CRPD Committee in expulsion cases. On the contrary, the Committee has so far shown some hesitation in applying the full range of disability rights to persons with disabilities who face expulsion. In particular, the CRPD Committee has placed strong reliance on the ECtHR's judgment in *Paposhvili v. Belgium* and therefore on the ECtHR's restrictive stance in so-called "medical cases." It has been argued in this chapter that the ECtHR's approach in these cases, with its almost exclusive focus on the severity of the illness and the availability of the required medical treatment, relies on a medical model of disability. The ECtHR has applied this restrictive approach – which includes a threshold of requiring a case to be "very exceptional" – not only to persons with disabilities, who have acute medical needs, but also to persons with disabilities in general, who may not have particular medical needs as in the case of the Afghan applicant in *S.H.H. v. United Kingdom*. In addition, the recent Grand Chamber judgment in *Savran v. Denmark* has clarified that the Court does not consider the refoulement prohibition in Art. 3 ECHR applicable to persons with disabilities in most circumstances.

The recommendation has therefore been for the CRPD Committee to look to its specialized counterparts of other UN human rights treaties, particularly the CRC and CAT Committee's case law in cases involving medical and rehabilitation needs and develop its own approach to refoulement cases of persons with disabilities. In addition, some aspects of the Committee's decisions so far indicate that the CRPD Committee may be readier than may appear to fully protect persons with disabilities who require international protection. These relate to the limited deference the CRPD Committee accorded to national authorities in *Z.H. v. Sweden* concerning the evidentiary assessment and the different CRPD violations which may bar a person's removal mentioned first and most clearly in *O.O.J. v. Sweden*, but reaffirmed, though in a qualified manner, in subsequent decisions.

Yet, this will not constitute a widening of the scope of the refoulement prohibition. Rather, such an approach will provide for the necessary disability-sensitive interpretation of *non-refoulement* and realize the full impact of the CRPD for persons with disabilities in removal situations, who are among the most marginalized and disenfranchised members of society, and thereby also render the human rights model of disability a reality in the context of refoulement.

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Inclusive Processes for Refugees with Disabilities: Improving Communication for Deaf Forced Migrants

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Laura Smith-Khan

Contents

Abstract

The coming into force of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) has created an opportunity to evaluate and re-design responses to forced migration, on both domestic and international levels. Indeed, since the creation of the CRPD, international and domestic

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organizations have taken a number of steps to make their processes more inclusive. Communication is fundamental to almost every aspect of refugee-related processes, from registration, through status determination, to needs assessments and resettlement evaluations. Ensuring that asylum seekers and refugees, including those who are deaf or hard of hearing, are able to effectively communicate and access information throughout these processes is thus a crucial prerequisite to them being able to enjoy their rights.

The chapter first briefly summarizes the key international legal provisions governing the procedural and communication-related rights of refugees with disabilities and explores recent updates to UN Refugee Agency guidance in this area. It then examines existing scholarship that demonstrates the central importance of effective communication to the crucial refugee status determination (RSD) process. This is followed by an exploration of existing research on disability in forced migration, with particular attention to communication involving refugees who are deaf or hard of hearing. The chapter concludes with a discussion of possible next steps within research and practice best to ensure inclusive and effective communication and thus to promote the enjoyment of procedural rights and access to protection for deaf refugees and asylum seekers.

Keywords

Asylum · Deaf · Hard of hearing · Sign language · Interpreting · Credibility · Communication · Refugee status determination

Introduction

> At the reception center there was another (asylum seeker) who came from the same hometown. . .as me. He got asylum fast! I was surprised and asked and wondered why, he did not lie. . . . we got a negative decision. Allah, we still hope. . . . He is hearing! He can speak. He can speak easily and powerfully. I can't (speak). I am deaf and I have to repeat my signing many times and it is hard. (quoted in Sivunen, 2019, pp. 11–12)

International Human Rights Law requires that all asylum seekers have the opportunity to participate in processes for refugee status determination (RSD) and to access protection on an equal basis with others. In RSD interviews and other hearings and appeal processes, communication is often pivotal. Being able to express oneself, and share one's experiences and fears in a convincing way, is often crucial to gaining protection. While the challenges of communicating across cultural and linguistic diversity have been widely acknowledged, how deaf people fare in these processes is much less documented. The experiences shared by deaf asylum seekers in a recent study in Finland (Sivunen, 2019), including the one cited above, provide rare and valuable insight into the potential inequalities in these all-important processes. However, beyond such exceptional research, much remains to be examined to adequately identify and address issues within these processes.

To elucidate what is currently acknowledged, required, and known regarding the participation of deaf and hard of hearing refugees[1] in decision-making processes, this chapter explores and brings together a combination of three analyses. First, it examines current international laws and standards that apply to RSD processes and other official interactions to better understand how the rules address the rights of deaf refugees. Second, following this, it summarizes transdisciplinary scholarship on communication in RSD processes to clearly set out the main concerns identified in this area. As this examination demonstrates, however, there is very little research specifically incorporating disability and even less particularly focused on the experiences of deaf people in these processes. For this reason, the third part of the analysis examines a broader body of research focused on refugees with disabilities generally, and deaf refugees more specifically, to uncover what *is* known about their experiences communicating in official encounters. The final part of the chapter reflects on these three analyses in combination and discusses the implications and next steps for both policy and practice and for research. It finds that across both these areas, there is still much to be done to ensure that deaf refugees can really enjoy their rights to participate and communicate in migration processes, and thus to access protection, on an equal basis with others.

International Rights and Rules on Communication and Procedural Fairness

International Rights

While the CRPD does not mention refugees and asylum seekers specifically, article 11 creates obligations on states "to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters." It is now well established that this provision applies to forced migrants and creates obligations not only for states parties but also for UN bodies, such as the UN High Commissioner for Refugees (UNHCR) (Crock et al., 2013; Crock et al., 2017, Chap. 2; Schulze, 2010) (for an extensive analysis of the relevant international rights framework, see ▶ Chap. 84, "Disaster and Climate Change-Induced Displacement of Persons with Disabilities: A Human Rights Perspective," by Kälin, in this Volume). The existence of the CRPD rights in forced migration is crucial, as the CRPD explicitly addresses a number of

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[1] Throughout this chapter, I refer to deaf refugees and asylum seekers, and refugees with disabilities or disabled refugees, with an understanding that different individuals identify with different terms and have diverse naming practices. In many contexts, deaf people may identify primarily as being a member of a linguistic and cultural minority group and may or may not identify as being disabled. However, for some, the experience of disability is created or exacerbated through particularly difficult social, political, and legal structures, such as those common in situations of forced displacement. See, e.g., discussion in McAuliff (2021).

rights not contained within the Refugee Convention, yet essential to the enjoyment of the rights contained within the latter.

Underlining the importance of accessible procedures in migration processes is article 18, on the liberty of movement and nationality. This provision requires that individuals "[a]re not deprived, on the basis of disability, of their ability . . . to utilize relevant processes such as immigration proceedings" (art 18(1)(b)). Article 21 reinforces the need to take practical steps to ensure rights to "receive and impart information," requiring States parties to "take all appropriate measures." The provision goes further by listing concrete examples of such measures. These include "Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions" (art 21(b)) and "Recognizing and promoting the use of sign languages" (art 21(d)).

Also relevant to accessible RSD processes are the fundamental, overarching CRPD principles such as the article 2 obligation to make reasonable accommodations and the article 9 accessibility obligation, which includes specific requirements to ensure that communications and information are accessible (see, e.g., subsections 2(d), 2(e), and 2(f)). The CRPD also emphasizes the right of disabled people to legal capacity (article 12(2)), requiring that "measures relating to the exercise of legal capacity respect [individuals'] rights, will and preferences" (article 12(4)). It likewise requires ensuring effective access to justice "including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants" (13(1)), made possible through the provision of appropriate training for officials working in the justice system (13(2)).

As will become clearer in the below analysis, the article 24 right to education is also of crucial importance. It requires appropriate accommodation and measures to ensure access to education for disabled people on an equal basis with others (art 24(5)), in order "to facilitate their full and equal participation in education and as members of the community" (art 24(3)). Among other things, this explicitly requires "facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community" (art 24(3)(b)).

This combination of provisions makes it clear that deaf refugees and asylum seekers have equal rights to participate in RSD and related decision-making processes on an equal basis with others. Further, and crucially, the CRPD repeatedly stresses throughout these provisions that these rights are unlikely to be realized unless State and non-State actors take multiple specific, concrete steps to ensure deaf people's equal opportunity to participate.

UNHCR Rules and Guidance

Recognition of these participation rights and obligations is reflected on an international level in progressive reforms to UNHCR policy and guidance documents, notably commencing with the introduction of "Need to know guidance: Working with Persons with Disabilities in Forced Displacement" in 2011 (for further exploration of disability-related reforms, see ▶ Chap. 87, “Disability and Refugee Protection,” by Crock in this volume). This guidance includes an instruction to “use appropriate information, dissemination and communication” and lists examples of how this might be achieved (page 13). It further acknowledges that persons with disabilities “have the right. . .to participate in all humanitarian activities, including documentation, registration and legal status” (p. 7). To achieve this, it suggests, inter alia, that staff should “make all reasonable efforts” to ensure access to services, including through the provision of information and communication (p. 8).

The next notable reform addressing inclusive participation came in 2013, with the development of a focused *Resettlement Assessment Tool* (UNHCR, 2013b). Alongside instructions on assessing individuals’ resettlement eligibility, the Tool requires staff to make both information about resettlement and the resettlement interview itself accessible for people with disabilities. For the interview, this means that “All accommodations must be made during the interview to enable refugees with disabilities to participate and ensure that their wishes and needs are considered fully.” It instructs staff to consider individuals’ specific needs when preparing for the interview, and “assess whether specialized interpreters or aids are required,” and also suggests that additional time may need to be allocated (p. 7).

Finally, in 2020, UNHCR updated its *Procedural Standards for RSD (UNHCR, 2020)*. This update removed some problematic language that reflected a medical-model approach to disability, such as references to “suffering” from disability. Significantly, this updated version now includes extensive guidance on the participation of applicants with “mental health concerns or intellectual disabilities” (see section 2.9). This section stresses the need to take all reasonable steps to ensure that applicants with mental health conditions or intellectual disabilities are able to meaningfully participate in the RSD process. It reminds staff of how these conditions may affect recall and the way in which applicants recount events and sets out specific procedural safeguards, accommodation, and support measures. These include, inter alia, identification and protection interventions and provision of “clear, accessible and easy to understand information about the RSD process and procedures, and adequate support to present their refugee status claims” (para 2.9.2(b)). They require that “information [about rights and obligations] must be provided in accessible formats and language” (para 2.9.2(b)) and recommend that all staff involved in RSD procedures involving applicants with mental health conditions or intellectual disabilities should be appropriately trained to do so (para 2.9.2(c)).

Guidance around assessing capacity to participate has been greatly improved from the 2003 standards, commencing with a statement that people should not be excluded just because they have a mental health condition or intellectual disability. Further, staff are instructed that before the interview, specific measures and accommodations should be explored to “maximize effective participation” and “The Applicant’s capacity to understand the RSD process and procedures should inform the way the RSD Interview is conducted, in particular the interviewing techniques and communication methods.” It also suggests that breaks, short interviews, postponing discussion of traumatic events, including a support person, and/or assigning an alternative officer and/or interpreter may assist (para 2.9.2(g)).

However, while such advice could undoubtedly benefit many refugees, there remains little specific discussion of how deaf asylum seekers should be accommodated or, indeed, consideration of vision or speech-related disabilities that may also affect communication or access to information. While there are no mentions of deaf people in the Standards, there are two mentions of people with hearing impairment. One relates to the potential inappropriateness of conducting interviews via telephone or video conference with “Applicants who have specific needs or vulnerabilities, in particular children, persons with hearing or visual impairment or mental health issues. . .” (section 4.3.2) The Standards also suggest that someone “suffering” from a hearing or speech impairment may require a “third party” to attend an interview “in order to facilitate communication” (section 4.3.4). However, there is no specific mention of using sign languages, and 4.3.4 does not explicitly state that such a “third party” could include a sign language interpreter.

Considerations related to recruiting, training, and including appropriate sign language interpreters are not raised. However, there is extensive guidance on the use of interpreters more generally (see section 2.5). This contains important principles for all asylum seekers, including the foundational requirement that “all communications between an Applicant and UNHCR must take place in a language that the Applicant understands and in which he/she is able to communicate clearly” (2.5.1). There are also warnings against using unqualified people or family members as interpreters whenever possible. The Standards advise that decision-makers should be particularly cautious when evaluating credibility in situations where the applicant does not have a UNHCR-employed and qualified interpreter (2.5.3). These cautions are particularly pertinent for forced migrants who may use a particular signed language from their country of origin that is not commonly used in the host country or who use family home sign (for an introduction to and discussion about home sign, also called homesign, and other sign language-related terms, see, e.g., Hou & Kusters, 2019).

Similarly, UNHCR’s Handbook on Procedures and Criteria for Determining Refugee Status (2020) identifies “mentally disturbed persons” as a group that may give “rise to special problems in establishing the facts” (paras 206–212). Children with disabilities are also noted as requiring “whatever mode of communication they need to facilitate expressing their views” (para 71). However, the Handbook does not elaborate regarding procedures to the same extent as the Procedural Standards, and there is no specific mention of considerations for people who are deaf or hard of hearing.

Recent developments in international law emphasize ensuring the equal and fair participation of people with disabilities in decision-making processes that affect them. Reform in UNHCR policy has followed suit, introducing guidance to improve the way UNHCR officials conduct refugee-related procedures and offering influential standards for domestic asylum agencies. In many ways, these guidance texts reflect the issues identified and emphasized in an increasingly large body of scholarship on communication in refugee-related procedures, which the next section explores.

Communication in Refugee-Related Procedures

The central importance of language and communication in refugee-related procedures is well established across a wide range of scholarship. Much of this literature focuses on RSD and more specifically on the interview, hearing, and statement-writing processes associated with producing what is often called the refugee or persecution narrative. As early as Walter Kälin's (1986) foundational article on cross-cultural misunderstandings in asylum hearings, scholars and practitioners have shared an appreciation for the complex yet pivotal nature of communication in these processes.

Yet significant challenges remain to this day. Scholars across multiple disciplines, from law, through psychology, to linguistics, emphasize the difficulties inherent in eliciting and assessing a narrative suitable for the purposes of determining whether an applicant meets the refugee definition set out in article 1A(2) of the 1951 Convention (or a domestic law equivalent). The types and sources of these difficulties are multiple but perhaps unsurprising, given that intercultural communication is a common feature of RSD processes and that they often involve people who have experienced forms of trauma (UNHCR, 2013a, p. 30).

That RSD processes often heavily emphasize assessing applicants' credibility increases the centrality of communication. This is because many of the indicators for deciding whether applicants and/or their narratives are believable rely on particular assumptions about what an honest person's communicative performance should look like. For example, credible narrators are generally expected to recount "logical, linear" stories (McKinnon, 2009, p. 213), and at times there is an overreliance on this expectation, despite guidance warning of the many reasons why consistency may not be possible (see, e.g., UNHCR, 2013a, p. 164). Researchers continue to contest such an overreliance on narrative consistency, pointing to the fact that it is rare for *anyone* to recount stories consistently over time (Cohen, 2001). They also point out that both individual and cultural diversity means that what asylum seekers remember and the way they make sense of their experiences may differ significantly from decision-maker expectations (Evans Cameron, 2008; Jacquemet, 2011).

Cultural differences can also influence whether a decision-maker finds elements of the narrative plausible (Sweeney, 2009). For example, decision-makers may not accept the way a particular applicant assesses risk or responds to a threat. This can stem not from these reported behaviors being untrue, but rather from the gap between a decision-maker's own life experiences and cultural viewpoint and that of an applicant (Dowd et al., 2018; Herlihy et al., 2010). Further, applicants' identities may be viewed in essentialized ways, with stereotypical assumptions about their ethnic, national, religious, or social group influencing decision-maker expectations about how they should think and act (Anker, 1992; Blommaert, 2001; Maryns, 2013; Smith-Khan, 2017a).

The particular language of the RSD interview and/or the language of interpreting are also important considerations that may be overlooked or underacknowledged. For example, research has documented the amplified potential for miscommunication when the applicant and/or the decision-maker is using their non-primary language or when they have a different language dialect, variety, or accent from each other and/or from the interpreter. These factors have led to significant misunderstandings that create apparent narrative inconsistencies which can prove fatal to an applicant's success (Maryns, 2005, 2006).

Interpreting also often plays a central role in RSD interviews, yet the nature of interpreting, and the many potential impacts of having an interpreter participate in these processes, remains underappreciated in many cases. Putting aside cases of dialect difference, poor interpreting, and errors (on these, see discussions in, e.g., Smith-Khan, 2020, 2021b), even the best interpreting entails a range of linguistic choices. It is practically impossible for a particular sentence or even sometimes one word to have only one possible translation. Interpreters also make decisions related to relaying tone and emotion as these also affect the creation of meaning and may be pivotal to the assessment of credibility (Inghilleri, 2003; Tipton, 2008; van der Kleij, 2015).

Moreover, interpreters are people and thus bring to any interaction their own beliefs and personal attributes which inherently influence the way that others perceive and interact with them (Merlini, 2009; Pöllabauer, 2004). Most obviously, this can affect how comfortable asylum seekers feel when sharing intimate or traumatic aspects of their experiences or identity, especially when they stem from being a member of a stigmatized group (see, e.g., Smith-Khan, 2019a, p. 408). Power asymmetries may also mean that asylum seekers become aware of interpreting issues but do not communicate this to the decision-maker in the moment (see example in Smith-Khan, 2017b) or that the interpreter may not feel comfortable interjecting to explain difficulties or complexities in the interpreting process (Cho, 2021a, 2021b).

Other factors may also prevent or delay asylum seekers from disclosing information about themselves or their experiences that may be important for their claim. Delayed or limited disclosure can be related to trauma (Herlihy et al., 2010) or not feeling comfortable sharing personal information with a lawyer, interpreter, and/or decision-maker who they have just met (Kenny & Fiske, 2004; Smith-Khan, 2021b). Applicants may believe that a particular experience is not relevant to their claim or that the decision-maker may not understand it (see, e.g., Bohmer & Shuman, 2007, who discuss a woman escaping female genital mutilation). Yet, delayed disclosure can be harmful to an applicant's credibility, and some jurisdictions specifically block applicants from providing additional details about their experiences or identities after their initial claim is made. For example, in Australia, fast-track review processes for asylum seekers who arrive without a visa rarely allow applicants a fresh hearing (McDonald & O'Sullivan, 2018). Further, decision-makers must draw an unfavorable credibility inference if new information is provided at the review stage without "a reasonable explanation" for why the information was not provided earlier (section 423A of the *Migration Act 1958* (Cth)).

Finally, access to and quality of legal assistance can make a significant impact on the way applicants are able to communicate their claims (Crock et al., 2020). Existing research identifies a number of communication-related roles that migration lawyers play, both directly, by drafting submissions and making oral statements, and indirectly by managing and mediating their clients' and other participants' interactions throughout the procedures (Jacobs & Maryns, 2021; Reynolds, 2020; Smith-Khan, 2020, 2021b). However, these roles have been found to be underacknowledged at both policy and individual case levels, once again leading to applicants being held responsible for factors beyond their individual control (Smith-Khan, 2021a).

This section provides only a brief overview of the myriad ways in which communication, the refugee narrative and assumptions about these, may have an impact on credibility assessment and RSD. What is clear from this substantial, interdisciplinary area of study is that there remain challenges with communication in RSD at two levels. First, the relevant law, policy, or guidelines may not adequately address the complex factors introduced above. Second, even if these documents address these factors, their practical implementation may be lacking or inconsistent. This has the potential to negatively affect RSD at multiple stages. Understandings about communication influence the rules and processes around choosing a language in which to conduct RSD interviews and identifying and booking a suitable interpreter in an appropriate language or dialect. When credibility issues arise due to linguistic reasons, applicants and lawyers who are able to identify and raise these, either during the interview or later in an appeal, will only be successful if decision-makers' beliefs about communication and credibility align with these reasons (Smith-Khan, 2019b, 2022).

It is for this reason that many scholars recommend that RSD processes should emphasize giving applicants the benefit of the doubt and rely much less heavily on scrutinizing credibility (Evans Cameron, 2018; Luker, 2013; Ruppel, 1991; Smith-Khan, 2019b). However, politics that increasingly seek to restrict and reduce numbers of asylum claims mean that many are skeptical about this fundamental shift becoming a reality (see, e.g., discussion in Bohmer & Shuman, 2007, Chap. 4).

Set against the communication complexities evident in this large body of interdisciplinary scholarship is the scarcity of accommodations for, and research about, asylum seekers and refugees who are deaf or hard of hearing.

Research on Deaf Refugees and Communication in Decision-Making

Very little research on communication in RSD or other refugee-related procedures explicitly addresses how people with disabilities fare in these processes. The significant exception is those studies exploring the role of trauma and mental health (e.g., Byrne, 2007; Cohen, 2001; Healicon, 2016; Hunter et al., 2013; Kenny & Fiske, 2004). This may perhaps explain the similar emphasis in the updated UNHCR Procedural Standards, where the most significant changes relate to mental health and intellectual disability. This section summarizes the research that *does* address considerations for people who are deaf and hard of hearing within refugee-related procedural communication.

A number of existing studies have explored the application of the CRPD on how refugee law is interpreted in RSD processes, for example, examining how a well-founded fear can be established, how disabled people can be considered a social group, and how disabled people's experiences may constitute persecution (e.g., Dimopoulos, 2016; Peterson, 2014). Some have also examined the requirements the CRPD creates regarding how RSD procedures are conducted. Those studies that have explored procedural requirements identify and discuss the obligations created by the CRPD (e.g., Camino Morgado, 2019, examining international and domestic law relevant to Peruvian RSD processes; Crock et al., 2013, who examine these obligations more globally).

Rarer are studies that explore the accommodation of disability in RSD procedures empirically. In fact, the literature search undertaken for this chapter identified no studies involving first-hand observations of RSD interviews or hearings that focused on the accommodation of disability generally or deaf participants specifically. Perhaps this should be unsurprising, since such interviews are notoriously difficult for researchers to access, given the sensitivities of this setting (Nikolaidou et al., 2019). However, there is an emerging body of scholarship that explores the experiences of refugees with disabilities in institutional encounters. This includes qualitative research with refugees and asylum seekers, including some focused specifically on deaf people and others interested in disabled people more broadly. Further, other studies focus specifically on the experiences of deaf refugees, but, more broadly, beyond institutional decision-making processes (see McAuliff, 2021, for an excellent literature review). The combination of these bodies of work provides significant preliminary insights into key interrelated considerations and issues for deaf asylum seekers in RSD. These center around access to adequate interpreting, access to language acquisition and training, access to community participation and advocacy, and discrimination and disclosure.

Access to Adequate Interpreting

A key issue identified in existing research is the paucity of appropriate interpreting services for deaf asylum seekers during RSD processes. This includes asylum settings in the global north, where the provision of accredited interpreters is usually the norm. Researchers in both the UK (Roberts & Harris, 2002; Ward et al., 2008) and Finland (Sivunen, 2019) have noted a complete lack of availability of sign language interpreting in RSD and related institutional interactions in asylum seekers' sign languages of origin. Ward, Amas, and Lagnado cite a participant from a disability organization who reported that the Home Office did not provide interpreting or a relay service for deaf people and questioned "how do we know whether deaf people are expressing themselves in their applications and explain why they come to this country?" (Ward et al., 2008, p. 55).

The UK studies both noted that there was even a shortage of interpreters fluent in British Sign Language (BSL). This reflects what the World Federation of the Deaf (WFD) and World Association of Sign Language Interpreters (WASLI) have called a "global problem," noting that "the number of qualified sign language interpreters is very small in most countries" (WFD & WASLI, 2014, p. 1). Discussing deaf migrant children, they (along with other partners) have also noted that while migrants are generally provided with interpreting in a language they understand, deaf migrants are rarely afforded this right (WFD et al., 2016, p. 4).

Even where sign language interpreters are booked for RSD interviews, this can have limited success as the host country's sign languages are often completely unknown to the applicants, who are likely to use very different languages (Sivunen, 2019). In other cases, interpreters qualified in the spoken language(s) of the individual's country of origin are booked for appointments and interviews, with an expectation that asylum seekers know the language and can sufficiently rely on lip reading or literacy in this language as a means of communicating in these high-stakes interactions (Sivunen, 2019). A documented example of the latter is cited in a case study of an Iranian family in Australian immigration detention who were all profoundly deaf and were provided with a Persian spoken language interpreter and expected to lip read in their interviews and without access to their required hearing aids (Australian Human Rights Commission, 2014, p. 68).

At the other end of the spectrum, Olsen's study on interpreting with deaf refugees in Norway exemplifies a more concerted attempt to provide adequate interpreting in government service settings. She describes the complex cooperative processes Norwegian Sign Language (NTS) interpreters report using to overcome the difficulties interpreting for refugees who have limited knowledge of NTS. This requires relay interpreting, involving both a hearing interpreter (to work to and from Norwegian and NTS) and a second deaf interpreter, who is generally more capable of improvised communication with the asylum seeker. In combination, she explains how the two interpreters, along with the official and the refugee, are able to negotiate meaning and understanding. Additionally, the hearing interpreter explains to the official what is happening and sensitizes them regarding the complexity and limitations of the communication process. As she explains, this makes it "possible for the hearing official to grasp the extent of the linguistic obstacles the interpreters and deaf refugees are facing" (Olsen, 2019, p. 21). Such an approach is crucial to avoid holding the applicant responsible for inconsistencies and issues with detail that may emerge as a result of these obstacles.

The provision of appropriate sign language interpreters and/or hiring officials with relevant language skills varies greatly from place to place and organization to organization, with these practices seeming to be more the exception than the rule (Crock et al., 2017). For example, in Jordan, it was found that multiple organizations working with Syrian refugees had lists of sign language interpreters they called on when required, and UNHCR's resettlement office had an employee who knew Jordanian Sign Language, which is mutually comprehensible with its Syrian counterpart (Hendriks, 2008). In contrast, officials at a camp in Turkey explained that they did not have any sign language interpreting services and that they managed this by relying on family members of deaf people to communicate on their behalf as needed (Crock et al., 2015, p. 32).

Access to Language Acquisition and Training

An additional and interrelated challenge for the provision of appropriate interpreting is the barriers to language acquisition and education that deaf asylum seekers (and many other deaf people) face. They may have experienced significant barriers to acquiring a sign language in their life before fleeing their home country, through social isolation and barriers to education. This is an issue that has been identified across a number of studies, focused on refugees from diverse countries of origin. Having limited opportunities to acquire and maintain a national sign language in their home country obviously creates significant difficulties. It also reflects a broader global issue: only a minority of deaf people worldwide have access to education in signed languages and face relatively high rates of limited literacy and lower rates of access to education more broadly (Holmström & Sivunen, 2022).

Participants in various studies described using home sign or gestures to communicate with family members and relying on family to communicate with broader society on their behalf (Roberts & Harris, 2002; Sivunen, 2019; Ward et al., 2008). This leads to practices that contravene international standards, such as relying on spouses or other family members to communicate on behalf of deaf family members or to interpret for them. Such practices often reflect and reinforce gender- or age-based power inequalities, for example, with husbands speaking for wives and parents speaking for (adult) children (Crock et al., 2015; Sivunen, 2019; WFD et al., 2016; Youngs, 2010).

Unfortunately, barriers to language education and language use persist for many after seeking asylum too. Research has found that deaf asylum seekers' experiences during RSD, and when attempting to access government services, can vary greatly depending on their access to training in the sign language of the host country, and their access to other deaf people, with whom they can acquire and improve their sign language skills. Sivunen (2019) found, for example, that while all asylum seekers in Finnish reception centers should not only be able to, but are actually obligated to, attend language classes, no such classes had initially been provided in Finnish Sign Language (FinSL) for her research participants. This meant that deaf asylum seekers were effectively excluded from language training and therefore restricted from access to information and participation in processes and society on an equal basis with other asylum seekers.

In settings where there are a high number of deaf refugees, schools for deaf people or deaf units within mainstream refugee schools have been established, as is the case for refugee children in Dadaab and Kakuma refugee camps in Kenya (Le Maire, 2018b; Youngs, 2010) and deaf Bhutanese refugees of all ages in Nepal (Women's Refugee Commission, 2015). While education in the host country's national sign language may be available for deaf refugee children in many settings, such education is generally much less common for deaf refugee adults (Holmström & Sivunen, 2022).

Conversely, access to language learning in the country of asylum, and social connection with other deaf people, can contribute to much greater participation within RSD processes and beyond and have a concrete impact on RSD outcomes. Sivunen shared reports of asylum seekers who, after having acquired FinSL, were able to look back on their RSD records and identify and correct significant miscommunications and errors that they earlier had simply not known existed. Key to improving access to FinSL language education were asylum seekers' contact with local deaf Finnish volunteers who managed to visit some of the reception centers and proved to be powerful advocates for change (Sivunen, 2019).

Access to Community Participation and Advocacy

Research on refugees with disabilities frequently invokes the often-under-utilized potential for civil society, including disabled people's organizations (DPOs), to support and improve the experiences of refugees and asylum seekers (e.g., Crock et al., 2017; Women's Refugee Commission, 2008, 2015). Sivunen's study found that deaf asylum seekers benefited in multiple ways when local deaf volunteers visited their reception centers. Deaf volunteers acted as language brokers between asylum seekers and reception staff, advocated for a number of changes within the centers, and connected asylum seekers with local deaf clubs. They were important providers of language training (and advocating for making this training available in the first place) and sensitized deaf asylum seekers on their rights in Finland related to using sign language in public and in official interactions, something that had not been the experience of all participants in their home countries. Local DPOs also have the potential to act more formally as key service providers. For example, in the case of Sweden, the Swedish National Association of the Deaf has an agreement with the government to assist in "the management and integration" of deaf migrants (WFD et al., 2016, p. 3). Research in Dadaab camp in Kenya similarly identified the Kenyan National Association of the Deaf as a key player in setting up "deaf units" within the camp (Youngs, 2010). Deaf children in Uganda's south-western refugee settlements were also reported to attend nearby local schools for the deaf, run by Uganda's National Association of the Deaf (Smith-Khan & Crock, 2018).

Lack of access to local disabled people was a common problem identified by my colleagues and I in our research project across six refugee-hosting countries (Crock et al., 2017). We found that while in some locations, disability civil society groups had a strong presence locally, they may have limited contact with or knowledge about the presence of refugees in their country. The most striking example in our study was in Malaysia, where we brought together representatives of various DPOs with representatives of local refugee community groups. DPO participants explained that they simply did not know that there were any refugees living in their country, nor did they know of any conflicts in neighboring countries that would explain their presence. The Burmese ethnic community leaders present were able to sensitize them about their persecution fears and experiences. In the case of Malaysia, we noted that urban refugees were thus often hidden in plain sight, throughout city areas, officially unacknowledged by the government, creating a significant social barrier from the kind of support that local DPOs could offer.

In other places, the (intentional) location of refugee camps and settlements in isolated areas, under strict security where it is difficult to gain permission to enter or exit, can create similar barriers to these types of local supports (see discussion in Mirza, 2014). This can be an ironic outcome in these locations, where an official justification for centralizing refugees in a controlled setting like this is that it is easier to provide a range of services on-site. In practice in our research, we found that this meant that in some locations, camps may have a variety of free medical services, for example, but the geographical and social isolation from local communities can mean that other supports, like those offered by deaf volunteers in Sivunen's study, are completely absent. Sivunen (2019, p. 8) notes the level of isolation and access to community for different individuals varied significantly based on whether they were located in a regional or metropolitan reception center. Similarly, UK policies of dispersal have been identified as barriers to important supports for disabled asylum seekers. For example, Ward et al. (2008, p. 55) noted that the Royal Association for Deaf People provided a range of services for asylum seekers and refugees, including training in BSL and legal advice and advocacy. However, their London location meant that deaf asylum seekers and refugees who were in other locations had more significant geographical/financial difficulties accessing services than their non-deaf counterparts, who were more likely to be able to access local services. Likewise, policies that determine support based on visa status can mean that services available to resettled refugees may not be available for asylum seekers or those on a temporary visa (see, e.g., discussion in Federation of Ethnic Communities' Councils of Australia et al., 2019; Hirsch et al., 2019).

In contrast, where there is greater scope for community building, both between local people and refugees and within refugee groups, studies report more positive outcomes. For example, in Uganda, a number of projects aimed at empowering refugees with disabilities had led to the development of several refugee DPOs within the settlements and within the urban refugee community in the Ugandan capital, Kampala. These groups received support from local organizations, such as the Refugee Law Project (based at Makerere University), which give them opportunities to meet, and access training, and also assist them in domestic RSD processes by providing them with sign language interpreters (Crock et al., 2017). Similarly, cooperation between Jordanian authorities and a local institute for the deaf has led to the provision of education and support for some deaf children in Za'atari camp for Syrian refugees (WFD et al., 2016, p. 3).

In other camp settings, such as camps in Kenya (Le Maire, 2018a, 2018b; Youngs, 2010), deaf refugees of different countries of origin, living together and interacting with each other in daily activities and building a deaf community identity, have created opportunities for the acquisition of multiple sign languages, including those of the host country, the sign languages of refugees from different countries of origin, and the development of camp-specific sign languages. This can mean that individuals are more likely to have access to a sign language that they understand in their interactions with officials.

Disclosure, Identification, and Discrimination

Another key issue identified for refugees who are deaf or hard of hearing when navigating institutional processes relates to the appropriate identification of their disability. This is generally a prerequisite to organizing appropriate accommodations.

It is widely acknowledged that organizations tasked with RSD and providing other assistance to refugees have not always systematically identified disabilities or done so in ways which adequately identified the particular supports or adjustments required to ensure that the organization was meeting their obligations to provide equal access and support (see Smith-Khan et al., 2015, for an extensive discussion on identification).

In some cases, a medical approach to disability may create extra-bureaucratic barriers to identification for deaf people, for example, requiring refugees to acquire hearing test results (at their own expense) to prove that they are deaf or hard of hearing as a prerequisite to this being officially recorded and accommodated (Smith-Khan et al., 2015).

Also significant are the fears and risks around disclosing disability due to the potential for a range of discrimination to occur if their disability is identified. One notable form is policy-based discrimination, when it comes to applying for a visa or accessing resettlement. In her study with deaf migrants in Victoria, Australia, Willoughby noted that some participants did not disclose hearing impairments or deafness due to their fear that it could affect their chances of being selected for resettlement in a third country, like Australia. This fear often continued to have negative impacts post-settlement, as some participants noted that they continued to not disclose and not request supports because they were afraid of potential negative repercussions for their visa (see discussion in Willoughby, 2015). Visa-related fears are not unfounded, given the historical and ongoing discrimination against disabled refugees in international and domestic law and policy in many contexts (Crock et al., 2017; Hirsch et al., 2019; Mirza, 2010; WFD et al., 2016).

Beyond problematic policy, studies have identified other reasons for not disclosing disability (Smith-Khan et al., 2015). Willoughby's study mentioned fears related to social stigma, and similarly, research with Bhutanese refugees with disabilities in Nepal noted a perception that deaf refugees were at higher risk of experiencing sexual violence (Women's Refugee Commission, 2015).

Reluctance to disclose and the broader failure of officials to identify and make suitable accommodations have obvious implications for asylum procedures. Applicants are closely scrutinized on their communication, and in such a situation, miscommunication has the potential to be both substantial and unidentified and therefore harmful for applicant credibility.

Reflecting on RSD, Communication, and Credibility for Deaf Refugees

There has been very little research conducted specifically exploring the experiences of asylum seekers and refugees who are deaf or hard of hearing in RSD and other official decision-making processes. However, some implications emerge from the scholarship, rules, and standards examined above.

One key observation from the large body of literature on language in credibility assessment is that when rule-makers and/or decision-makers underestimate the complexity of communication or have problematic beliefs about how language works, this can cause problems for *all* asylum seekers' participation in RSD processes. Their linguistic needs may be underestimated, and they can be held responsible for misunderstandings that arise not due to their lack of credibility, but rather because of insufficient accommodations within these processes. For example, not having access to adequate legal assistance is a commonly identified problem that can have a serious impact on the development of an asylum seeker's narrative. The research in this section suggests that deaf asylum seekers may be more likely to be expected to communicate in a language or dialect that they do not understand sufficiently and be provided with inadequate sign language or spoken language interpreting. Similarly, the previous section's literature acknowledges the barriers to disclosing sensitive or traumatic information, and once again existing research suggests that such barriers may be exacerbated when disability affects communication, even outside RSD processes (Marshall & Barrett, 2018).

The additional geographical, financial, linguistic, and social barriers identified above suggest that many of the problems and complexities identified in the linguistic research are likely to be even more common and acute in the case of deaf asylum seekers. However, this potential has only just begun to be addressed and explored in policy and practice and in research.

Next Steps

Policy and Practice

The CRPD is a revolutionary document in that its primary function is not to create additional rights, but rather to clearly acknowledge that disabled people, including forced migrants, are rights holders on an equal basis with others. Its emphasis on protecting, promoting, and ensuring these rights is apparent throughout the treaty, especially in the inclusion of many explicit obligations to take concrete measures. It is not enough that disabled people have rights in theory. Making these rights *real* is essential (Bruce, 2015; Schulze, 2010). The rights of disabled asylum seekers and refugees are no exception.

However, this chapter has uncovered ongoing challenges and opportunities on multiple levels. At the level of international standards, there have been significant steps to acknowledge the rights of disabled people in refugee responses, including in official interactions and decision-making. However, this process is ongoing, including when it comes to addressing the practices and accommodations deaf refugees may require to ensure equal participation in procedures. The general procedural standards around communication, language choice, and interpreting undoubtedly apply to *all* asylum seekers and can undoubtedly help ensure the rights of deaf people. However, so far, the CRPD approach of specifying concrete measures to overcome common barriers for disabled people has mainly concentrated on addressing mental illness and intellectual disability. This is an important addition and will hopefully pave the way for adding explicit measures and standards to better ensure the rights of other disabled refugees and asylum seekers, including those who are deaf or hard of hearing.

At the level of practical implementation, emerging research on the experiences of deaf refugees indicates that barriers to equal participation do indeed exist in practice, in a range of settings. However, particular positive examples also offer insight into better practices. Notably, and unsurprisingly, these studies demonstrate the value of investing in, empowering, and listening to deaf people themselves – including refugees and asylum seekers, local deaf organizations, national and international civil society, and deaf researchers.

Research

A wealth of research on linguistic considerations in RSD processes has provided valuable insight for scholars, legislators, policy-makers, and decision-makers and arguably has influenced some improvements in international and local policy and practice. Additional empirical studies involving people with disabilities and deaf people seeking asylum would prove an important addition to this growing body of scholarship and likewise provide an important foundation for continuing reform, and some such studies are already underway (see Holmström & Sivunen 2022 for an overview of such studies).

Such research would help to identify examples of good practice that may be happening on a domestic level, within UNHCR or government asylum agencies. Domestic asylum agencies may also have law, policies, or guidelines that more comprehensively address the participatory rights of deaf asylum seekers throughout the decision-making process. A comparative study across different jurisdictions – on the level of both policy and practice – and/or a comparison between the two levels in one or more jurisdictions could be a good point of departure.

Further studies could also identify potential challenges that have not been found or examined in the existing broader language-in-asylum scholarship. Ethnographic research examining RSD interviews with deaf and other disabled refugees would complement comparative legal and policy studies. While there are institutional challenges with gaining access to be able to collect data in this setting, and linguistic challenges conducting research with deaf refugees, scholars who have worked in this area show that it is possible and provide a promising model for future projects. In existing research, this has included mobilizing their own linguistic skills in the research and using innovative communication methods with their research participants. These methods can also provide important insights into best practice for decision-makers in terms of communicative choices and interpreting meaning from their encounters with deaf participants (see Sivunen & Tapio, 2020, for an important discussion on these points). Such research would help develop crucial evidence to inform, and to advocate for, more positive changes. It would thus contribute toward making procedural rights real for deaf refugees.

Cross-References

- ► Disability and Refugee Protection
- ► Disaster and Climate Change-Induced Displacement of Persons with Disabilities: A Human Rights Perspective

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Women and Girls with Disabilities in the Heart of the COVID-19 Crisis: Safeguarding Sex and Reproductive Health Rights

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Edwin O. Abuya and Naomi Njuguna

Contents

Abstract

The COVID-19 pandemic exacerbated the human rights challenges that women and girls with disabilities faced (and continue to face). This chapter reviews the impact of the epidemic on this vulnerable population. It focuses on their sex and reproductive health rights, using Kenya as a case study. Although these entitlements are guaranteed by the international human rights framework and provisions of domestic law, the situation on the ground is precarious for this cohort of individuals. In the wake of the COVID-19 crisis many have continued to face several human rights violations, including discrimination and stigma, as well as the inability to access health facilities or obtain appropriate information on the

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pandemic from the officials. These infringements compromise their sex and reproductive health rights. In order to stem these infractions, the chapter reviews some of the interventions that duty bearers can take. To conclude, the chapter contends that these players need to take practical steps in order to deal with the challenges caused by pandemics such as the COVID-19 crisis.

Keywords

COVID-19 · Women and Girls with Disabilities · Sex and Reproductive Health Rights · Violations · Interventions

Introduction

Persons with Disabilities have faced (and continue to face) several violations of their fundamental rights and freedoms (see, for instance, Abuya and Githinji (2020–2021) and Gulnara et al. (2015)). The situation is precarious for women and girls with disabilities ('WGWD'). Despite legal guarantees, practical experience shows that State and Nonstate actors often violate their basic rights (see Olaleye et al., 2012; Opoku et al., 2016). In the developing world, the situation is more worrying. In the context of sex and reproductive health rights (SRHR), WGWD face serious challenges in their quest to enjoy these entitlements. Compared with able-bodied individuals, WGWD have more health care needs. During emergencies such as the current COVID-19 pandemic, the situation is more risky for this vulnerable population. Many face discrimination, violence, and threats to their dignity, economic entitlements, and privacy rights from state and nonstate actors (Al-Ali, 2020; Samaila et al., 2020; Mbazzi et al., 2021). Accessing the relevant support services is also a huge challenge during such disasters (Saalim et al., 2021).

Sex and reproductive health rights are of utmost importance for a number of reasons. Access to relevant information enhances the ability of WGWD to make informed decisions about their bodies. Further, the provision of contraceptives contributes a great deal towards WGWD making informed choices about their lives and livelihoods. These rights are critical in safeguarding the rights of WGWD to manage their sexuality. In addition, these entitlements are integral in arming individuals with information on the avenues available if their rights are violated. Further, information on SRHR enables WGWD to avoid or deal with the consequences of sexually transmitted diseases. Moreover, these rights are useful in securing the right of WGWD to enjoy sex like any other individual. For these reasons it is essential that the SRHR of WGWD should be protected and promoted at all times. Failure to safeguard these rights has serious consequences.

In order to advance the SRHR of WGWD robust international and domestic legal frameworks have developed. These frameworks, which apply in all situations, create two obligations – a positive and a negative obligation. Under the terms of the former Governments are required to take steps to ensure that WGWD enjoy their SRHR at all times. The negative obligation prohibits the State from taking any measure that will erode the enjoyment of this right.[1] To this end, the international legal framework contains a rather comprehensive regulatory framework, which sets out the obligations for the realization of health rights for all individuals. This includes the SRHR for WGWD. Under the international legal framework, Governments are required to guarantee the right to health at all times. Beginning with the 1948 *Universal Declaration of Human Rights* (UDHR)[2] subsequent treaties, including the *United Nations International Covenant on Economic and Social Cultural Rights*[3] (*ICESCR*), *Convention on Elimination of All Forms of Discrimination Against Women*[4] (*CEDAW*), the *Convention on the Rights of the Child*[5] (*CRC*), and the *African* (*Banjul*) *Charter on Human and Peoples Rights* (*ACHPR*)[6] secure the right of every person to health. The *ICESCR* and *CRC* in articles 2 and 4 respectively capture the general obligations framework at the international level.

These treaties envisage that member states will utilize both domestic (public and private) and international resources (that is, the 'maximum available resources') to achieve the realization of SRHR for WGWD. At the continental level, article 16 of the *Banjul Charter* requires States in Africa to ensure that 'every individual' enjoys the 'best attainable state of physical and mental health.' Further, this positive obligation calls on Governments to 'take necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick'.[7] Under the terms of this treaty African States bind themselves to, primarily, 'recognize the rights, duties, and freedoms' contained in the Charter.[8] Further, they undertake to implement these obligations through adoption of 'legislative and other measures'.[9]

For WGWD in particular, the 2006 *Convention on the Rights of Persons with Disabilities* (*CRPD*),[10] contains a robust protection framework. The preamble

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[1] See also Justice Makau of the Kenyan High Court in *Bloggers Association of Kenya (BAKE) v Attorney General and 3 Others; Article 19 East Africa and Another*, Petition No. 2016 of 2019 [2020] eKLR at para 39 (affirming this rule).

[2] Adopted by the UN General Assembly Resolution 217A (III) on December 10 1948 (*UDHR*) article 25.

[3] Adopted and Opened for Signature, Ratification, and Accession by General Assembly Resolution 2200A (XXI) of 16 December 1966 (Entry Into Force 3 January 1976) (*ICESCR*) article 13.

[4] GA Res. 34/180, 34 UN GAOR Supp. (No. 46) at 193, UN Doc. A/34/46 (1979) (*CEDAW*) article 11.

[5] Adopted and Opened for Signature, Ratification, and Accession by General Assembly Resolution 44/25 of 20 November 1989 (Entry Into Force 2 September 1990) (*CRC*) article 24.

[6] Adopted by the Organization of African Unity Resolution 67/3 (Entry into Force 21 October 1986) ('*Banjul Charter*') article 16.

[7] See article 16.

[8] Article 1.

[9] Ibid.

[10] *The UN Convention on the Rights of Persons with Disabilities*, Adopted by the United Nations General Assembly Resolution 3447 of 13 December 2006, Opened for Signature on 30 March 2007 (Entry into Force 3 May 2008) ('*CRPD*').

recognizes the importance of WGWD being able to access health facilities. This is seen as a way toward enabling them to 'fully enjoy all human rights and fundamental freedoms.'[11] Article 25 of the *CRPD* demarcates the boundaries of the right to health for WGWD. In addition to recognizing this right, the article also calls on States to ensure that WGWD enjoy this entitlement at all times, without discrimination.

It is simplistic to claim that, because the international legal framework does not expressly mention the SRHS for WGWD, these rights are not recognized by international and regional laws. This reasoning is simplistic. On the contrary, these rights, which are provided for by reference, are captured under the wide umbrella of the right of access to health. The second reason why this claim fails lies in the primary objective of these legal instruments. This framework was designed to promote, protect, and safeguard human rights for all persons at all times, and in all spaces. Consequently, would it not be absurd to contend that the SRHR of WGWD are excluded from this corpus of law? Last, state practice affirms the principle that WGWD are entitled to protection of all their rights under the terms of the international and regional laws (Committee on the Rights of Persons with Disabilities (2018); *Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa*, adopted at the Thirtieth Ordinary Session of the Assembly, Held in Addis Ababa, Ethiopia on 29 January 2018).

Meeting legal obligations requires Governments to invest resources in programs and projects that are geared toward safeguarding SRHR for WGWD. During unprecedented times like the one the world is experiencing currently, the level of resources should be enhanced. This is essential if these rights are to be realized on the ground. Yet evidence shows that initiatives that are designed to safeguard the SRHR for WGWD are inadequately resourced. The record of countries in the developing world is quite troubling (Kabia et al., 2019; Mwimbi, 2017; Gichuna et al., 2020). In Kenya in particular, the public health system is in crisis. In its 2018 Annual Report, the United Nations Development Program noted that poverty remained at a 'high level' in the country (United Nations Development Program, 2021 at 7). According to this report, between 2015 and 2016, the poverty rate was about 36% overall (United Nations Development Program, 2021 at 7). In the northern part of Kenya the figure was almost double. About 70% of the residents in this area lived below the poverty line (United Nations Development Program, 2021 at 7). In the context of health, The World Health Organization estimated in its 2019 report that just under one third (about 30%) of Kenyans had access to basic sanitation services (World Health Organization, 2021). Government investment in the health sector has been unimpressive. In its 2018/2019 to 2020/2021 report, the Kenyan Ministry of Health Working Group identified 'inadequate funding' as one of the key challenges.[12] During the 2018/2019 period, the Ministry was allocated just over half of the funds it had requested.[13] Resource gaps are also noticeable at the

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[11] Preambular paragraph (v).

[12] World Health Organization, 2021, at 24.

[13] Ibid.

local levels. In its 2018 report, Kenyatta National Hospital, the main referral hospital in the county, reported that between 2017 and 2018 it had a financial deficit of approximately Kenya Shillings one billion (US$ ten million) (Kenyatta National Hospital, 2018 at 51). Similarly, the National Council for Persons with Disabilities reported deficits of approximately Kenya Shillings 60 million (US$ 600,000) and 500 million (US$ five million) in the 2017–2018 and 2016–2017 financial years respectively. The reduction in resource allocation had a drastic effect. Its net impact is to limit the scope of implementation of, among others, projects that are designed to benefit WGWD. When COVID-19 struck in 2019 it found a health system that was already besieged. This disaster worsened an already dire situation (Worldbank Group, 2021 at para 1.1.4 ('The health system is facing an unprecedented challenge to contain the spread of COVID-19 and care for the infected')). For this cohort, access to SRHR is crucial. Hence, the adverse health situation caused additional problems.

At the beginning of 2020, there were just over 500,000 WGWD (or 1.3% of the total population) in Kenya (Kenya National Bureau of Statistics, 2021 at 393). This chapter reviews the extent to which the Kenyan Government has met its obligations to WGWD in the wake of the COVID-19 tragedy. It focuses on SRHR. The paper contends that the State has failed to meet its primary obligation of providing sufficient resources for programs designed to meet the SRHR of WGWD living in the country. Despite the launch of the Universal Health Coverage Program (UHC) in 2018, as part of the incumbent Kenyan Government's Big Four Agenda, allocations for health care have remained significantly low.

The chapter is divided into five sections. The section "SRHR for WGWD: Rights and Obligations" reviews the obligations framework. In other words, which legal duties are placed on the Government with regard to according WGWD their SRHR? Issues surrounding the allocation of sufficient resources are also evaluated in this section. This issue is at the heart of any program that is designed to meet the right under review. As noted earlier, this cohort faces serious challenges in accessing their rights. The section "Interventions to Safeguard the SRHR of WGWD During the COVID-19 Pandemic: Three Proposed Strategies" evaluates some of these difficulties. In the section "Conclusion: Beyond the Rhetoric" the strategies that an aggrieved person can invoke to ensure compliance, are analyzed. Focus is placed on three key measures – strategic litigation, human rights education, and policy interventions. This section considers the benefits and limitations of each strategy. To conclude, the chapter contends that the law in the books needs to be matched by actual practice, if WGWD are to enjoy their SRHR during this difficult period.

SRHR for WGWD: Rights and Obligations

This section reviews two fundamental issues – the material content of Kenya's legal obligations with regard to safeguarding the SRHR for WGWD as well as according sufficient resources to these programs and projects. The section also examines key processes that the Government can adopt to ensure that the statutory rights are translated into actual practice.

Securing the SRHR for WGWD

As the situation in international law, Kenya's legal framework recognizes the SRHR of WGWD. Beginning with the Constitution, article 21(1) creates an obligation on Government agencies to 'observe, respect, protect, promote, and fulfil the rights and fundamental freedoms in the Bills of Rights.' The State is also obliged to take 'legislative, policy, and other measures including the setting of standards to achieve the rights guaranteed under Article 43,'[14] which includes SRHR. State agencies are also required to 'address' the needs of WGWDs, as a category of 'vulnerable' persons.[15] Further, the national values that guide operations in the country include 'human dignity, equity, social justice, inclusiveness, equality, human rights, and non-discrimination'.[16] These are basic principles that all institutions need to embrace at all times. More specifically, WGWD are entitled to be treated with dignity and respect in all areas,[17] including realization of their SRHR. They should also have access to materials and devices that can enable them to overcome the obstacles created by their disabilities.[18]

Like some countries in Africa,[19] Kenya has passed a national disability-related legislation. The 2003 *Persons with Disabilities Act* ('*PDA*') is a comprehensive piece of legislation that is designed to address the special needs of WGWD. Although this statute does not recognize directly the right to health services, it makes reference to this entitlement. Section 20 entitles the National Council for Persons with Disabilities ('Council') to be represented in the Ministry of Health national health program agenda. The terms of reference of this policy framework are rather broad. Among other tasks, it is designed to:

(a) Enable persons with disabilities to receive free rehabilitation and medical services in public and privately owned health institutions;
(b) Make available essential health services to persons with disabilities at an affordable cost;
(c) Make available field medical personnel to local health institutions for the benefit of persons with disabilities;
(d) Ensure prompt attendance by medical personnel to persons with disabilities.

Against this background, it is apparent that the *PDA* covers health rights in general. This position is consistent with the overall objective of the statute, namely,

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[14] Article 21(2) Constitution of Kenya 2010.

[15] Ibid article 21(3).

[16] Article 10(2).

[17] Article 54(1)(a) of the Constitution.

[18] Ibid article 54(1)(e).

[19] See, for instance, the *Discrimination Against Persons with Disabilities (Prohibition) Act, 2018,* (Nigeria), *Persons with Disability Act, 2006* (Ghana), *Disability Law No. 10* (Egypt), *Disability Act* (Sierra Leone).

to ‘provide for the rights’ of WGWD.[20] Further, as a signatory to the *CRPD* and the *ACHPR*,[21] Kenya is obligated to safeguard the rights of WGWD, including their SRHR.[22]

Other domestic pieces of legislation, particularly the 2017 *Health Act*, also contain a robust legal protection framework. Under this statute the Health Minister is charged with the responsibility of implementing the constitutional right to health.[23] Like the Constitution, this statute mandates the State to ‘observe, respect, protect, promote, and fulfil the right to the highest attainable standard of health.’[24] More specifically, section 68(1) of the *Health Act* requires the Minister to ‘devise and implement measures to promote health and to counter influences having an adverse effect on the health of the people.’

The *Health Act* also recognizes the importance of guarding SRHR. To this end, this legislation requires the Minister to formulate a comprehensive legal program that will guarantee protection of these rights. According to this Act, an appropriate plan should cover the following key areas[25]:

(i) Effective family planning services.
(ii) Implementation of means to reduce unsafe sexual practices.
(iii) Adolescence and youth sexual and reproductive health.
(iv) Maternal and neo-natal and child health.
(v) Elimination of female genital mutilation.
(vi) Maternal nutrition and micro-nutrient supplementation.

In October 2019, Kenya’s Senate House introduced the *Reproductive Health Bill 2019* (‘*RHB*’).[26] Although the Bill is yet to be passed, it is notable that it sets out a robust framework for the facilitation of access to reproductive health services by WGWD. The *RHB* seeks to expand on the foundational principles that are set out by the *Health Act*. In its preamble, the proposed legislation outlines three central objectives. In the first place, it seeks to ground the right to reproductive health care into Kenya’s legal framework. Further, the proposed legislation is designed to set local standards of reproductive health. Last, the *RHB* seeks to provide for the right to make decisions regarding reproductive health. These are the overarching

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[20] Preamble to the Statute.

[21] Article 2(6) of Kenya’s Constitution declares that any treaty ratified by Kenya is automatically part of domestic law. See also *Karen Njeri Kandie* vs *Alssane Ba & Another* Petition No, 2 of 2015 [2017] eKLR (where the Supreme Court of Kenya affirmed this basic rule).

[22] Article 25 of the Constitution.

[23] Section 15(1)(c).

[24] Section 4.

[25] Section 68(1)(e).

[26] Available at http://www.parliament.go.ke/sites/default/files/2020-02/Reproductive%20Healthcare%20Bill%2C%202019.pdf (Accessed 6 November 2021).

goals of the intended legislation. In terms of meaning, the Bill defines in clause 2 several terms, including:

> "Reproductive health" means a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes.
>
> "Reproductive rights" include the right of all individuals to attain the highest standard of sexual and reproductive health and to make informed decisions regarding their reproductive lives free from discrimination, coercion, or violence.

These frameworks are crucial at many levels. Primarily, they flesh out the material content of this SRHR. Additionally, they set standards for compliance. Further, they demarcate the boundaries of this entitlement. For duty bearers these canons are important because they mark out the boundaries of their obligations. Justice seekers can also invoke them to assess the extent to which SHRS have been met (or remain unmet), and measures that they can take to promote compliance. In the case of any violation these principles provide useful leads regarding individuals against whom an aggrieved party can seek remedies.

Human Rights in Provision of Adequate Resources Framework

What obligations does Kenya have in relation to allocating sufficient resources for programs and projects that are designed to promote the SRHR of WGWD? This is the central question, which this section evaluates. Usually, Governments fund their operations from loans (external and internal) as well as taxes and other levies. Taxes on income are imposed typically on residents and nonresidents who meet set legal criteria.[27] Upon collection, the income is distributed to various expenditure streams. Kenya's Constitution has an elaborate system for revenue collection and allocation.[28] In their resource allocation mandate, the Constitution requires national and county governments to take into account the special needs of WGWD. Article 201 of the Constitution outlines principles and frameworks of public finance. Governments at all levels must observe these fundamental rules. In keeping with this rule, they are required to have a system that seeks to promote 'an equitable society.'[29] Among others, the resource allocation framework should make 'special provision for marginalized groups and areas.'[30] Meeting this legal obligation requires both levels of government to ensure that sufficient resources are allocated to WGWD. In times of emergencies, the level of support should be increased to match the growing needs.

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[27] Section 3 of the Kenyan *Income Tax Act*.

[28] See part 3 of chapter 12 of the Constitution.

[29] Ibid Article 201(b).

[30] Ibid.

Initiatives designed to allocate sufficient resources to health programs play a key role in the realization of SRHR. Adequate resources are always needed to achieve the progressive realization and implementation of the socio-economic rights of all members of society. The concept of progressive realization acknowledges the resource challenges that low- and middle-income countries face in seeking to realize and implement these rights.[31] Even so, this language should not be used as an excuse by countries such as Kenya to delay according WGWD their SRHR, and, thereby, expose them to the adverse effects caused by the denial of health care. On the contrary, meeting legal requirements requires the Government to demonstrate the steps it had taken to comply with its basic obligations.[32]

Kenya's domestic law imposes an obligation on the State to provide sufficient resources for programs designed to meet SRHR of WGWD. As mentioned earlier, article 43 of the Constitution guarantees this right. Special provisions are also made for vulnerable individuals such as children. Under article 53, girls with disabilities are entitled to, among other rights, 'health care.' Granted, article 54 of the Constitution, which focuses on persons with disabilities (PWDs), does not mention the right to health. This is not to imply, however, that the framers of the Constitution failed to appreciate the value of access to SRHR by WGWD. On the contrary, and in keeping with article 21(3), the Constitution requires all individuals as well as State and non-State agencies[33] to treat WGWD 'with dignity and respect.' Courts in Kenya have also construed this fundamental right broadly.[34] Consequently, it is apparent that this umbrella provision covers the fundamental obligation to accord WGWD their SRHR. A contrary interpretation would be absurd, considering the clarion call of Kenya's National Anthem – *Haki iwe Ngao na Mlinzi* (translated: Justice be our Shield and Defender). An aggrieved party can also invoke the general right to health provision contained in article 43(1) of the Constitution to advance a case for the Government's compliance with this fundamental right. An obligation is also imposed on county governments to safeguard the SRHR of WGWD,[35] including providing adequate resources for the actual realization. Other local laws, including the *Children Act*[36] and the *PDA*[37], reinforce the constitutional framework.

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[31] UN Committee on Economic Social and Cultural Rights, 'General Comment No. 14' on 'The Right to the Highest Attainable Standard of Health (Article 12)' UN Doc E/C 12/2000/4 at paras 30–31.

[32] Article 21(2) of the Constitution and section 11 of the *PDA*.

[33] Article 21(3).

[34] *Paul Pkiach Anupa and Another v The Hon. Attorney General and Another*, Petition No. 93 of 2011 [2012] eKLR; *Anthony Kipkorir Sang v The Hon. Attorney General*, Cause No. 2408 of 2012 [2014] eKLR (where the High Court (Justices Majanja and Mbaru respectively) defined the right to dignity to cover employment rights).

[35] Articles 185–187 of the Constitution read together with part 2 of the Fourth Schedule.

[36] Section 12 ('A disabled child shall have the right to be treated with dignity, and to be accorded appropriate medical treatment').

[37] Under section 20 'health' is one of the rights of children with disabilities.

The Constitution obligates the Government to implement all the rights due to WGWD. Meeting this test requires an examination of the measures the Government has taken. The standard for evaluating these measures, as Judge Mumbi established in *Consumer Federation of Kenya (COFEK) v The Attorney General and Others*, is that of reasonableness.[38] One of the preliminary steps the Government has to undertake is to allocate sufficient resources to meet the SRHR of WGWD. It is not enough for the State, which bears the burden of proof,[39] to claim that it has insufficient resources to implement this right. Rather, it must demonstrate that resources are unavailable.[40] In the context of resource allocation, again, the burden of proof is on the Government. This time round it will have to demonstrate that it gave 'priority to ensuring the widest possible enjoyment of the right or fundamental freedom, including the vulnerability of particular groups or individuals'.[41] The Kenyan High Court (Ngugi J) in *Luco Njagi & 21 Others v Ministry of Health and 2 Others*[42] was emphatic on the State's obligation:

> It is thus undisputed that the state has the primary obligation to ensure that the petitioners and other citizens enjoy the highest attainable standard of health. The state has a duty to make the necessary budgetary allocation, as well as to take the necessary legislative and policy measures, to ensure that the right to health is realized.[43]

Other domestic laws contain provisions governing the allocation of resources for health programs. In particular, the *Health Act*,[44] which was designed to, among other things, regulate the provision of health care services, creates an obligation for the State to allocate resources to finance health projects across the country. This piece of legislation dedicates an entire part to this aspect, hence underscoring the importance that the Government should attach to issues relating to the implementation of SRHR for WGWD. Compliance with this basic rule requires Government to take the following measures:

- Develop policies and strategies for the realization of universal health coverage;
- Undertake cost-sharing mechanisms at the county level;
- Develop an appropriate public health financing framework that caters for reimbursements of health care providers who respond to disasters and emergencies;

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[38] [2012] eKLR at para 47.

[39] Section 107 of the *Evidence Act* of Kenya.

[40] Article 20(5)(a) of the Constitution.

[41] Ibid, sub-section (b).

[42] Petition No. 218 of 2013 [2015] eKLR.

[43] Ibid at para 67.

[44] No. 21 of 2017.

- Develop a standard health package that is financed through prepayment;
- Provide a framework to secure health care needs for vulnerable groups and indigents.[45]

Although the *PDA* lacks a comprehensive allocation framework, it underlines the value of resources as a way of fulfilling the rights due to WGWD. Section 20 of this legislation recognizes the importance to implementing SRHR. The Council is charged with the responsibility of advancing the special needs to WGWD in the implementation of the national health program. Issues surrounding resource allocation and utilization would ordinarily fall under this provision.

Resource Allocation and (Prudent) Utilization

Several pertinent questions arise when one examines processes and programs that are designed to fulfil the SRHR of WGWD in general and in times of crisis. What are the potential sources of resources? Once they have been sourced, how are resources to be utilized? Why? Are there any needs that should be prioritized? What is the basis for placing or excluding an item from the list? Which resources are required for each item? The third question relates to sustainability of the resource streams, which have been identified. How long can the sources last? Last, there are questions relating to the monitoring and evaluation of the target projects. How will these projects be assessed in order to determine whether or not they have delivered on their mandate? Were the resources used in an efficient, transparent, and accountable manner? How will the impact of a project be measured? The remainder of this part responds to these questions.

The highest allocation of resources to the health sector in Kenya has been seen during the coronavirus epidemic. A portion of the allocated resources were dedicated to the Universal Health Coverage ('UHC') program (Health Policy Plus, 2021). Interestingly, within those allocations, there is little direct mention of or provision for SRHR for WGWD. Like many low- and middle-income countries, Kenya has over the years relied on donor aid to finance its budget for health. Following the global coronavirus pandemic, the level of funding from the international community shrunk drastically. In order to cushion WGWD from the risks and vulnerabilities caused by the epidemic, the Government had to step in. Its allocation was necessary to plug the gap that had been left in the budget. Even so, the amount of resources allocated fell short of the proposed budget. Although the government identified the National Health Insurance Fund ('NHIF') as the vehicle through which the UHC project would be delivered, this State agency has had several challenges. In addition to governance issues, the fund has over the years been riddled with corruption scandals (R v Director of Public Prosecutions and 3 Others, Ex Parte Meridian Medical Center Ltd and 7 Others, 2015; Ethics and Anti-Corruption Commission, 2019).

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[45] Section 86 of the *Health Act*.

Moreover, the NHIF has an insufficient population base to make sufficient contributions for its purposes (Barasa et al., 2018 at 11). These factors cast serious doubts on the ability of the NHIF to deliver on this crucial mandate.

With decreased funding for health programs, Kenya has had to explore quickly alternative sources. Failure to take this step has serious consequences for WGWD. Local funding streams must, therefore, be explored and tapped to the fullest extent possible. Further, incidents of corruption must be reduced to an all-time low. Robust measures must be taken to combat this ill (see also Rispel et al., 2016 at 248). The resources that are saved from these initiatives should be ploughed into projects focusing on WGWD as well as the multiplier effects, which COVID-19 produced.

Once resources are generated they need to be allocated to various cost centers. Because resources are finite, it is imperative that the Government sets its priorities. The most pressing needs during the COVID-19 pandemic must be identified and addressed. Owing to scarce resources, one would expect the Kenyan Government to develop a priority list. All interested persons must be involved in this process (Africa Disability Alliance, 2015 (drawing a similar conclusion)). Gunjeet Kaur and others remind us that priority setting 'calls for processes that decide about allocation of resources between competing health programs' (Kaur et al., 2019 at 1). For the process to deliver, a bottom-up approach should be adopted (Mtapuri & Giampiccoli, 2016 at 162). Top-down approaches, by contrast, rarely meet the needs of the target community. In order to deliver the goods, the recepients must be involved at all stages of the planning process. As the well-known slogan in disability studies goes: "nothing for us, without us" (In Latin, they say, "*Nihil de nobis, sine nobis*"). Article 201 of Kenya's Constitution, which draws on article 13 of the *African Charter*, requires participation by stakeholders in all financial matters involving the State. Courts in Kenya have affirmed this basic rule.[46] This article also sets out the principles that should guide all aspects of management of public resources in the country, namely, transparency, openness, equity, and prudence in the way that State resources are used. Salome Bukachi and others (2014 at 349) assert that decision makers should consider the following factors as a guide toward setting priority areas: the importance of the health problem; availability of additional funds; cost effectiveness; cost-sharing measures; and core activities to be undertaken. The prevailing political climate is also a crucial factor that cannot be ignored.

In theory, the process of resource allocation appears simple and straight forward. However, in practice there are usually a lot of back-and-forth discussions before a budget is drafted, debated, and agreed upon. Orao-Lawrence and Wyss contend that priority-setting decisions are 'complex, value-based, and highly political' (Orao-Lawrence & Wyss, 2020 at 183). Priority consideration should be in the context of population demand, needs, and values. But in Kenya, unfortunately, priority setting

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[46] *Phillip Nyandieka (Suing on his own Behalf and on Behalf of the General Public) v Non-Governmental CDF-Bomachoge Borabu Constituency*, Petition No. 237 of 2018 [2019] eKLR.

is usually secretive (Barasa et al., 2017 at 105), ad hoc, and inefficient. This leads to insufficient and ineffective use of health resources. It also causes inequities in health resource distribution, leaving out the most vulnerable people, such as WGWD. As experience shows, their SRHR are yet to be prioritized within the health budgets of the country. During the COVID-19 pandemic, the bureaucratic processes had to be executed expeditiously. Unlike in a normal situation, the Government had very little time on its hands. Thus, quick action had to be taken. At the same time internal accountability controls had to be adhered to, from start to finish. Otherwise, the rights of WGWD would continue to be severely undermined.

Sustainable Development Goal number 3.c reminds countries of the need to 'substantially increase health financing . . ., especially in least developed countries.' Meeting this goal requires stakeholders to include a sustainability plan in each project. This is a key factor that the Government (County/National) cannot afford to ignore. A wider perspective is important in ensuring that any health initiative delivers in the long term. Donor funding is quite fluid and 'unpredictable'.[47] This stream depends on the politics of the day. If the receiving and donating Government fall out, there is a high chance that funding will be immediately withdrawn or significantly reduced. We also need to be aware of the phenomenon that is commonly referred to as "donor fatigue." For donor-funded interventions, there is a need to formulate an alternative plan should these resources dry up. In other words, SRHR projects for WGWD must be designed to survive beyond the donor funds. Those projects that take a narrow financial approach are likely to face serious monetary challenges as time goes by. The end loser in such circumstances tends to be the target population. Proper planning is, therefore, crucial, if an SRHR project for WGWD is to survive in the long run. Following the COVID-19 catastrophe there were significant budget cuts. Most traditional donors diverted funds to their in-country programs. The knock-on effect of budget cuts was to drastically reduce resources for WGWD projects in Kenya. As mentioned above, these were already struggling. Hence, the reduction in international resources exacerbated further the vulnerabilities and risks that WGWD continue to be exposed to.

According to a 2019 report conducted by Pharos Global Health Advisors, Kenya is yet to develop a viable strategy to address the declining financial assistance in sexual and reproductive interventions, particularly family planning commodity supply (Pharos Global Health Advisors, 2019 at 56). There is also a lack of a transition strategy. Despite the fact that Kenya had attained the target of a 58% national modern contraceptive prevalence rate, the disparities across the regions cannot be ignored. For instance, in the northern part of the country, the prevalence rate is at 2%, whereas in central Kenya it is 80%. The report argues that these disparities 'may have diluted technical support for [Family Planning, FP], as partners have concentrated efforts and resources at the county level without commensurate

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[47] Republic of Kenya, Ministry of Health, *Health Sector Working Group Report: Medium Term Expenditure Framework (MTEF) for the Period 2018/19 to 2020/21* available at http://ntnt.treasury.go.ke/wp-content/uploads/2020/11/Health-Sector.pdf. (accessed: 8 April 2021) at 24.

engagement at the national level, where FP is technically stewarded' (Pharos Global Health Advisors, 2019 at 56).

Monitoring and Evaluation ('M&E') is an essential tool for checking whether the outcomes envisaged by certain interventions and programs are actually being met. "Monitoring" refers to 'the routine tracking of the performance of key elements of a program or project,' whereas "evaluation" means 'the systematic and objective review of an on-going or completed project to assess its effectiveness and impact' (Oyediran et al., 2014 at 443). Some of the M&E indicators that have been identified as useful for SRHR programs are clarity, relevance, specificity, and comparability. M&E facilitates transparency and accountability in the utilization of project resources. It is a strong weapon in the fight against corruption. When properly executed, this initiative can contribute significantly to the realization of SRHR by WGWD. Let us now look at some of the violations that the lack of inadequate resources leads to.

Violations Associated with the Lack of Inadequate Resources

For WGWD the lack of adequate resources in the health sector has caused further problems. The current system is ill designed to meet their unique needs. PWDs are generally excluded from health policies, strategies, and programs. In its 2008 research ($N = 14{,}569$), the National Co-ordinating Agency for Population and Development found that only 14% of women with disabilities aged between 12 and 49 years received family planning services.[48] Research conducted by Human Rights agencies based in Kenya drew a similar conclusion. The Kenya National Commission on Human Rights established in its 2014 study that women with disabilities faced several difficulties accessing reproductive health services (Kenya National Commission on Human Rights, 2014 at part 3.3.2). These included the negative attitude of health providers as well as the lack of information and proper facilities (Kenya National Commission on Human Rights, 2014 at part 3.3.2.). Similarly, the Government of Kenya acknowledged this exclusion in its 2021 report to the UN Committee on Persons with Disabilities:

> Women with disabilities encounter numerous barriers to accessing quality reproductive health care services. Some of the barriers include inaccessible equipment and service points, limited contraceptive options and insensitivity by health care workers among others.[49]

The COVID-19 pandemic worsened this situation. Although the law in the books requires the Government to allocate sufficient resources to programs that are designed to promote the SRHR of WGWD, the situation on the ground is markedly

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[48] National Co-ordinating Agency for Population and Development, *Kenya National Survey For Persons With Disabilities: Preliminary Report* (2008) part 3.9.

[49] U.N. Committee on the Rights of Person with Disabilities, Consideration of Reports Submitted by States Parties Under Article 35 of the Convention: Kenya, (3 April, 2021) para 256.

different. How does the inadequate resource situation impact the realization of SRHR by WGWD? The remainder of this section responds to this vital question. It discusses some of the effects caused by the inadequate or improper utilization of resources in the wake of the current pandemic.

Discrimination and Stigma

In its 2021 'Disability Inclusion Status Report',[50] the Kenyan Government identified stigma as a cause of concern. The nonprioritization of the health needs of WGWD exacerbates the stigma and discrimination that they face. Despite having sexual feelings, WGWD are seen as being asexual or in some cases hypersexual or incapable of having sexual relations or to reproduce (Powell and Stein (2016 at 56). See also Serges Kamga (2018)). This misplaced perception hampers any meaningful efforts for these individuals to realize their SRHR. Soft law, as reflected in the 1994 United Nations Standard Rules for the Equalization of Opportunities for Persons with Disabilities (UN General Assembly, 1994), is emphatic that the sexual relationships of WGWD must be respected and protected at all times, including during the COVID-19 situation. Rule 9(2), which deals with family life and personal integrity, states that:

> Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood. . . Persons with disabilities must have the same access as others to family-planning methods, as well as to information in accessible form on the sexual functioning of their bodies.

WGWD also face various socio-cultural barriers. Their sexuality is systematically stigmatized. They are seen as being without sexual desires and the ability to have marital and parental relationships (Schaff, 2011; Schenk et al., 2020). In their research on Kenya, Christopher Johnson and others argued that this belief eventually leads to 'their exclusion in many sexual and maternal health programs, including HIV/AIDS prevention, in developing countries' (Johnson et al., 2012 at 105–118 at 110). Contrary to legal requirements for equality, inclusion, privacy, and dignity to all persons, in some instances WGWD are reprimanded for having sexual relationships or getting pregnant (Morrison et al., 2014 at 1135). The cultural perception about a woman being the one who takes care of the home and her husband makes the situation worse for women with disabilities in Kenya. Research has documented that some WGWD face bullying and harassment at the hands of health care workers (Chinnery & Westboork, 1995). Yet article 27 of Kenya's constitution outlaws all forms of discrimination.

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[50] On file with the authors.

Lack of Autonomy, Dignity, and Informed Consent

As a well-known adage says, information is power. Article 35 of Kenya's constitution provides for the right of access to information (for a deeper discussion, see Abuya (2017)). The international human rights framework contains a similar provision.[51] Even so, there is a key difference between the enjoyment of this right at the local level and its international counterpart. In Kenya, the right of access to information is limited to 'citizens,'[52] whereas on the international plane there is no such limitation. Under the latter framework, the right of access to information is available to every person. This variance has a grave impact on foreign nationals living in Kenya. Under Kenya's Constitutional framework, State and non-State actors can lawfully withhold information in their custody from non-national WGWD. The impact of this is drastic, considering the many benefits that accrue from this entitlement (see Abuya (2013) at 215 to 244 at 215).

This state of affairs, however, is not to imply that Kenyan WGWD are in a better position. Although they are entitled to information, research shows that they, too, are denied access to knowledge and information about their sexuality, sexual behavior, and sexually transmitted diseases (Gona et al., 2018; Ingstad & Grut, 2021). Adequate data on the COVID-19 virus and its effects was, unfortunately, not provided (Ndavula & Lidubwi, 2021). This in turn is a huge barrier to accessing SRHRs (Ganle et al., 2020a). Absence of accurate and timely health information often leads to sexual marginalization of WGWD, irrespective of whether one is in or outside of an emergency. Their lack of awareness and proper information is likely to deprive them of the ability to exercise autonomy/self-determination over the medical decision-making processes regarding their sexual and reproductive health. Incidents of forced sterilizations and abortions as well as forced/unnecessary caesarean sections against WGWD have been reported (Durojaye, 2017; Wairimu, 2010). In some instances these violations take place with the collusion of family members (Faith Kasiva, 2021 at 5). Clearly, these practices are discriminatory. Eventually, they deny WGWD the right to make decisions regarding parenting and motherhood.

As a result of inadequate health personnel with specialized training, WGWD continue to face challenges with regard to their rights to confidentiality and privacy. Many are forced to attend hospital in the company of a family member, who usually offers escort and/or translation services (Lusweti & Wanyonyi, 2021; Owuor, 1995, Chap. 9). Although they may facilitate the hospital visit, this mode of operation is quite troubling. This state of affairs is less ideal as it tends to seriously erode one's confidence and esteem. Does this situation accord WGWD their fundamental rights to human dignity and equality, which the Kenyan constitution guarantees to all in articles 28 and 27? The response to this question must be in the negative. For patients who are unable to find a relative or any other person to accompany them to hospital,

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[51] *Banjul Charter* article 13; *ICCPR* articles 2(3) and 25; *UDHR* articles 8 and 21.

[52] Article 35(1). See also *Family Care Limited v Public Procurement Administrative Review Board and Kenya Medical Supplies Agency* [2012] eKLR.

the situation can be very precarious, particularly if they require urgent medical attention or specialized facilities, as is the situation during the current epidemic.

During this pandemic, the Kenyan Government, as many States, imposed several restrictions. A dawn-to-dusk curfew was imposed in the country. Additionally, protocols requiring social distancing in all public spaces were introduced. Although these containment measures were designed to check the spread of the virus, their unintended consequences on WGWD were drastic. In the first place, because public vehicles were now forced to carry fewer passengers, many hiked their fares in order to break even. Owing to years of marginalization, most WGWD have meagre resources (Trani et al., 2015; Ndlovu, 2016; Chitereka, 2010). Hence, many are unable to afford the increased fares, and, thereby, access health facilities. Second, these restrictions led to a reduction in the number of sitting spaces available in public vehicles. This in turn meant that one had to fight in order to board a vehicle. This reality caused significant problems for WGWD. Unless their escort was strong, they had to wait for several hours before they could travel to obtain medical services. Further, the fact that fares had increased meant that one required more resources in order to be accompanied. Moreover, the fact that one had to reach one's destination before the curfew hours kicked in presented further problems. Owing to these difficulties, it is reasonable to assume that some WGWD chose not to seek medical attention in facilities that required them to use public transportation. The consequences of such decisions can be life threatening.

Women and girls with disabilities are also at a greater risk of gender-based violence (Opini, 2012; Combrinck, 2017). The current disaster, as the authors established during informal conversations, worsened this situation. Combating this violation requires a number of interventions, including allocating adequate resources for establishing specific centers where victims or justice defenders can lodge official complaints. To bear any fruit these initiatives must take into account the particular susceptibility and vulnerabilities as well as unique needs of the victims in this case. Real and exhaustive investigations must be conducted for any complaint that is lodged. To be effective, law enforcement officials must be involved in these processes. If it is established that an offense was committed, the perpetrator must be charged and prosecuted in a court of law. Thus far, the government of Kenya is yet to establish such centers. The lack of access to the prevention sites can end up exposing further an extremely vulnerable group of its membership to acts of violence.

Barriers of Access to Health Services by WGWD

For WGWD to fully enjoy fully their SRHR they need to access health facilities with relative ease. Unlike their counterparts who are able bodied, special facilities have to be erected to enable them to gain entry and navigate any physical environment. Compliance with the legal requirements requires health facilities to ensure that the environment is accessible to all users at all times. To guard against discrimination, the *PDA* contains specific provisions. In the first place, the Minister of Health is represented in the Council.[53] As mentioned earlier, it is expected that the council will champion the SRHR of WGWD. Additional requirements exist in the context of access to and mobility within a health care facility. The *PDA* in section 21 requires public and private health facilities to provide a 'barrier-free and disability friendly environment'. This position is consistent with article 25 of the *CRPD*, which guarantees WGWD the right to health care.

Despite these legal guarantees, the situation on the ground is markedly different. As mentioned above, because of local transportation issues, accessing health facilities was very problematic during the pandemic (Neetu et al., 2021 at 65). WGWD continue to face barriers owing to the lack of disability-sensitive environments. In some settings where ramps are available, they are either built from the wrong materials or are too steep. These undesirable facilities pose several problems to those with mobility challenges (Mwirigi, 2017 at 70 (accessed: 7 November 2021; proposing construction of suitable ramps in order to improve 'accessibility of building infrastructure and sanitation accommodation')). In other instances, the examination beds are unsuitable for some patients, as they are too high or are ill designed to meet the needs of patients with disabilities. In her research on experiences of women with disabilities in health facilities in Nairobi City County ($N = 22$), Grace Mukasa found that high examination beds are a barrier in accessing facilities (Mukasa, 2008 at 31 (accessed: 7 November 2021)), especially for those with physical or mental disabilities. Some health facilities lack lifts (Ngugi, 2012). For WGWD with mobility challenges this is a huge impediment. Other amenities such as washrooms and beds can also be a challenge for those with physical disabilities. In many public sector health facilities, the washrooms are usually in a latrine format. Accessing these facilities requires those with physical disabilities in particular to crawl on the usually dirty floors (Asfaw et al., 2016). This undesirable condition is very troubling during the current COVID-19 pandemic. Indeed, it is a vector for spreading the virus. Doubtless, these circumstances are likely to lower the self-confidence and esteem of any individual. These violations also erode one's rights to dignity and respect (see also Zuurmond et al., 2016; Wasonga & Bukania, 2015). Further, the lack of sign language translators in most medical facilities is another area of serious concern, particularly for the deaf community (Lusweti et al., 2020). This situation is not unique to Kenya. See, for instance, (Ahumuza et al. 2014). Appropriate literature in braille, or in simple language, pictures, etc., for the intellectually disabled are also known to be lacking (Kenya National Commission on Human Rights, 2012; Ganle et al., 2020b).

Following the outbreak of the COVID-19, most governments established isolation/quarantine centers. These facilities were designed to house those who had tested positive or who were suspected of having been exposed to the virus. Once they tested negative they would be released. Although these steps were designed to check the spread of COVID-19, the centers posed serious challenges for WGWD. Compared with persons without disabilities, these individuals require special attention when

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[53] Section 4(1)(c) of the *PDA*.

admitted into hospital. As the isolation wards are closed to the public, all patients are required to fend for themselves. For WGWD, who rely on others for support, accessing drugs or amenities within these facilities was a nightmare (Nzeribe et al., 2018).

We also need to examine the personnel at a health facility. This inquiry requires us to review the staff composition within a health facility. Several questions come to mind: Does a particular health facility have enough personnel? Are they aware of the special needs of WGWD? Are the staff qualified to handle sex and reproductive challenges that WGWD face? Do the health care service providers have the requisite experience, training and skills for the job, especially during this global pandemic? These are some of the questions that could be asked to gauge the suitability or preparedness of a health facility.

Despite legal requirements for the provision of adequate resources for projects and programs for WGWD, unfortunately, many public hospitals in the country lack qualified health workers to handle patients with disabilities (Ndetei et al., 2011; Bor, 2021). Yet, in the wake of the pandemic, health care workers were required to possess special skills to handle patients. The lack of disability mainstreaming within the health services caused additional problems to WGWD who were admitted into these facilities. In addition to services, it is possible that confidential and sensitive information relating to sexual health was compromised. This could have discouraged some patients from seeking services in public hospitals. Patients who have visual and audio disabilities are particularly vulnerable as they have to rely on touch as well as mouthing words. This means they could not be masked at all times even though the COVID-19 containment protocols called for the wearing of masks by everyone in all public spaces.

Costs, including medical fees, are also a barrier to access to health services by WGWD (Kariuki et al., 2015; Kirigia & Sambo, 2003). Each time a patient needs medical care, there is a cost implication – transportation, consultation, drugs, and/or food. These are likely to escalate, depending on whether or not one is admitted into hospital. If admitted, one will be required to settle their medical bill before they can be discharged. If they don’t or fail to provide a guarantee of payment, a hospital facility can detain them.[54] They will only be released once they pay the bill.

Interventions to Safeguard the SRHR of WGWD during the COVID-19 Pandemic: Three Proposed Strategies

The barriers evaluated above must be checked, if WGWD are to enjoy their SRHR. This is more pressing in the COVID-19 environment. The task is huge. It cannot be left to WGWD alone. Rather, all human rights defenders must join hands. In this section the paper addresses strategies that stakeholders can deploy to ensure Kenya

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[54] See, for instance, *MAO & Attorney General & 4 others*, Petition No 562 of 2012 [2015] eKLR; *Emmah Muthoni Njeri v Nairobi Women’s Hospital,* Petition No 352 of 2018 [2021] eKLR.

complies with its legal obligations. It focuses on three interventions – strategic litigation, human rights education, and available policy interventions.

Strategic Litigation: Potential and Challenges

Strategic or public interest litigation[55] is one the strategies that WGWD and/or human rights defenders deployed to check infractions of the law by national or county governments during this global threat. This route can be used to hold these duty bearers accountable for their obligations to WGWD. This initiative is also a powerful advocacy tool (Roa & Klugman, 2014). The success of strategic litigation depends on at least three factors. In the first place, a country needs to have a robust legal or regulatory framework. Within this structure, the rights and duties of WGWD should be spelt out. For the legal framework to be effective it must identify the duty bearers. To put it in another way, which department(s) is/are responsible for allocating resources to programs, which are designed to safeguard the rights of WGWD during this difficult period? In the absence of these pointers it would be difficult to hold a duty bearer accountable in instances of alleged noncompliance.

The presence of an autonomous judiciary is the second key factor. Judges and magistrates who hear cases must be guided by the law, and the law alone.[56] Nonlegal considerations should be ignored when arriving at a judicial decision. Fidelity to the law is an important aspect of any objective judicial system. In Kenya, the National Anthem is emphatic that “haki iwe ngao na mlinzi.” When translated into English it means, “Justice be our Shield and Defender.” In keeping with this fundamental call, decision makers must have solid knowledge of the entitlements of this vulnerable group (Ashagre, 2020). A deep understanding of the domestic and international rights frameworks is also critical, if one were to decide a case progressively. One must apprise oneself regularly on the jurisprudence, which emerges from regional and international courts and tribunals.

Third, we need to consider the claimants who seek to air the rights of WGWD in domestic and international legal fora. As is well-known, the burden of proof usually lies with the moving party.[57] Jeremie Gilbert contends that those who lodge claims in court should be able to ‘articulate their rights.’ (Jeremie Gilbert, 2017 at 665) Although this author does not break down this assertion, WGWD, whether through counsel or in person, are required to bring on board sufficient evidence when they make allegations of violations of SRHR of WGWD. They must show instances of noncompliance with particular provisions of the law. Once they marshal this

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[55] This refers to a suit commenced in which a plaintiff is able to establish a special interest in the subject matter, notwithstanding that the subject matter also involves issues of public interest. See Peter Nygh and Peter Butt, *Butterworths Concise Australian Legal Dictionary* (Butterworths: Sydney, 1998) at 356.

[56] Article 160(1) of the Constitution (emphasizing that the Judges are subject to the ‘Constitution and the law’).

[57] Section 107(1) of Kenya’s *Evidence Act*.

evidence the burden shifts to the Government to show how it has met its legal obligation. Like decision makers, the legal representatives must have a solid grasp of the law (Sileoni, 2011 at 99). They must appreciate the entitlements that the Constitution sets out in the Bill of Rights. A solid understanding of the legal framework governing the protection of SRHS of PWDs, both at the local and international levels, is crucial, if the litigation process is to deliver for this clientele.

Courts are an important avenue for guaranteeing the protection of the SRHR of WGWD. When a case is properly framed and conducted, a court can grant a litigant the remedy they have sought. But this route is prone to several limitations. Litigants must take these, too, into account before they invoke this route. Primarily, the litigation process is expensive. In most legal systems the costs of hiring experienced counsel is not cheap. For litigants this is a huge barrier. WGWD are in a worse off position, considering that they have inadequate means. In the absence of pro bono legal services, many would be unable to enforce their SRHR. One would argue that in instances of violations these victims should represent themselves in court. This argument is simplistic. The Kenyan legal system is quite complex. It would be quite difficult for a lay person to navigate this maze. Hence, the need for a victim to be represented by experienced counsel. Further, court processes in Kenya tend to be very protracted. Despite the legal requirement that these procedures should be expeditious,[58] the reality is that cases take several years to be heard and determined.[59] This is expensive not only in terms of money, but also when one considers the time spent running a case. Yet the concern at hand, meeting the sex and reproductive health needs of WGWD in the current COVID-19 environment, requires urgent action. The fact that a losing party in the High Court can challenge an unfavorable decision in the Court of Appeal,[60] and, eventually, the Supreme Court[61], means that the road to an effective remedy can be quite long. In the meantime, the SRHR of WGWD will continue to be violated. It is also questionable whether this state of affairs prevents the well-known adage – justice delayed is justice denied.[62]

The third limitation of the court system lies in the kind of remedy a judge can hand down. Article 22(1) of the Kenyan Constitution states that:

> Every person has the right to institute court proceedings claiming that a right or fundamental freedom in the Bill of Rights has been denied, violated or infringed, or is threatened.

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[58] Section 1A(1) of the *Civil Procedure Ac* (Cap 21) and article 47(1) of the Constitution.

[59] The Kenyan Judiciary accepts this reality. See *State of the Judiciary and the Administration of Justice Annual Report, 2018/2019*. Available at file:///C:/Users/USER/Desktop/Financing%20Reproductive%20Health%20and%20PWDs/SOJAR%20REPORT%202,018%20_%202,019%20final.pdf (Accessed: 28 May 2021) at 24.

[60] Article 163 of the Constitution.

[61] Ibid. article 164.

[62] Article 159(2)(b) of the Constitution requires courts to be guided by the principle that 'justice shall not be delayed.'

Under article 23(1) of the Constitution, the High Court of Kenya is given authority to hear and determine such claims. After hearing a case a judge should grant an 'effective remedy.'[63] In Kenya, the following reliefs are available:

(a) A declaration of rights;
(b) An injunction;
(c) A conservatory order;
(d) A declaration of invalidity of any law that denies, violates, infringes, or threatens a right or fundamental freedom in the Bill of Rights and is not justified under Article 24;
(e) An order for compensation;
(f) An order of judicial review.

The concern here is not the nature of the reliefs, which a court can hand down. Rather, it lies in the fact that once a case is lodged in court, a judge has the final say, unless the litigants reach an agreement. Parties to a suit will thus have to contend with the court's decision. Herein lies the problem, particularly for common law legal regimes, which follow the precedent system. Under this framework courts are bound by previous decisions. Further, lower courts are bound by decisions of higher courts. Likando Kalakula describes litigation as an 'important strategy.' (Kalakula, 2013 at 169) But this author fails to appreciate the fact a court can set an unhelpful precedent. For common law systems the rules established by such precedents have to be followed by lower courts, unless the decision is reversed on appeal or review. Decisions from the apex court can only be overruled by the court itself. Otherwise, they are binding on the court and all lower courts.

Serges Kamga reminds us that litigants need to take into account the 'threat of litigation.' (Kamga, 2014 at 452) Invoking alternative dispute resolution mechanisms is one way that WGWD can explore to avoid courts creating "dangerous" precedents. In Kenya, article 159 of the Constitution recognizes reconciliation, mediation, arbitration, and traditional dispute resolution mechanisms as possible avenues for dispute resolution (see also Alternative Justice Systems Baseline, 2020). Considering the dangers associated with litigation (discussed above), it is prudent for WGWD seeking to enforce their SRHR to invoke these frameworks, prior to engaging the court framework. If they decide to lodge claims in court, the legal representatives running these claims should re-evaluate the evidence on record. They should give priority to the alternative justice modes. In addition to saving on resources, the alternative justice resolution tools give parties a chance to explore the most appropriate remedy for the dispute at hand. Moreover, a lay person can air his or her claims in these forums as the rules of evidence are not strictly followed (Yet these systems have attracted significant criticism. See, for instance, Kiplagat, 2016; Asunah, 2020; Amasah et al., 2015–2017).

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[63] Articles 8 and 2(3) of the *UDHR* and *ICCPR*, respectively.

The last limitation lies in issues surrounding compliance by the Government with court orders. This is yet another area of grave concern. Usually, when a Judge hands down a decision he or she will direct a party to the suit to perform a certain act or refrain from specific conduct. In the context of SRHR for WGWD during this period of the COVID-19 epidemic a court could make orders compelling a particular government official to take certain steps within a prescribed time-line. If it fails to abide, the aggrieved party can commence contempt proceedings against the official who has failed to comply with the orders of the court.[64] Failure to comply can lead a court to make additional orders. The issue of noncompliance with court orders is of grave concern in Kenya. Unfortunately, the record of the Government shows that it does not always comply with court orders.[65]

The trend of noncompliance with court orders by the Executive arm of the Government is extremely worrying. It sets a bad example for a country that prides itself in having a progressive Constitution. The preamble to Kenya's Constitution recognizes the aspirations of all citizens for a State based on 'essential values of human rights, . . . social justice and the rule of law'. The caseload cited in this section exhibits the Executive's reluctance to protect and preserve the Bill of Rights or abide by the justice call, which Kenya's National Anthem emphasizes. The open defiance of Court Orders casts serious doubt on the Executive's intention to embrace basic rule of law principles as well as promote a human rights culture in the country. Simply put, it is a 'culprit of human rights violations' (Mubangizi, 2005 at 179). The upshot of this trend is to potentially compromise a great deal the realization of SRHR by WGWD during these uncertain times.

Beyond Litigation: Human Rights Education

In Kiswahil they say, "Elimu ndiyo mwanga uongozayo kila shani." When translated to English it means, "With knowledge one can emerge from a difficult situation." Promotion of human rights education ('HRE') is the second strategy that justice seekers can deploy. According to the United Nations General Assembly, HRE refers to:

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[64] See the *Contempt of Court Act* (2016).

[65] See, for example, *Miguna v Dr. Fred Okengo Matiang'i and Others,* Constitutional Petition No. 51 of 2018 [2018] eKLR (where Judge Mrima quashed a decision by the Minister to revoke the petitioner's citizenship and suspend his passport); *Adrian Kamotho Njenga v The Attorney General and Others*, Constitutional Petition No. 369 of 2019 [2020] eKLR (where the High Court found that delay by the president to appoint individuals the Judicial Service Commission had proposed for judgeship was 'unreasonable and unconstitutional'); *Okiya Okoiti and Another v The Public Service Commission and Others* and *Law Society of Kenya v The Office of the Attorney General and Others*, Constitutional Petition No. 42 of 2018 [2021] eKLR (where the court declared unconstitutional the creation by the President of certain state offices and nomination of officials to these offices), and *Law Society of Kenya v The Office of the Attorney General and Others*, Constitutional Petition No. E283 of 2020 [2021] eKLR (where the court nullified an Executive Order by the President to transfer the responsibilities of a State Corporation to the Military).

> [T]raining, dissemination and information programs can have a catalytic effect on national, regional, and international initiatives to promote and protect human rights and prevent human rights violations (UN General Assembly, 2000).

In the context of WGWD this initiative is the learning process that focuses on their SRHR. The overall goal of HRE is to ensure that WGWD can appreciate, and, consequently, are able to advocate for their entitlements (see also Sibusisiwe Mavuso & Pranitha Maharaj, 2015 at 83). This is not to imply, however, that WGWD do not know what is good for them or what they would like to achieve. On the contrary, the goal of this strategy should be to ensure that the rights of these individuals are guaranteed in all spaces, by all persons and at all times. Emphasis should be on access to SRHR by WGWD. To this end, these educational platforms should seek to build on the current knowledge base that WGWD possess. Among other objectives, the trainers should provide new and 'innovative' (Burnett, 2021 at 12) strategies for addressing current challenges. Further, the platforms should be an avenue via which WGWD share their knowledge, skills, and experiences.

Moreover, these forums are useful for the wider community to appreciate the SRHR entitlements of WGWD. For those who deal with WGWD, these sessions are a powerful tool for arming them with relevant information and knowledge, which they use to engage their clientele. The overall objective is to empower these individuals to become 'subjects [or promoters] of rights' (Abraham Magendzo, 2005 at 140). This strategy promotes the *CRPD* call for health professionals to 'provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent (article 25(d)).' In order to be effective these information exchange forums should feed into the existing channels that WGWD use. Consistent with the well-known disability theme – "nothing about us without us" – instructors should be drawn from WGWD. Although national human rights commissions[66] and 'opinion leaders' (Sondem, 2015–2017 at 84) can be part of the process, a top-down approach should be avoided. On the contrary, WGWD should drive this initiative for real change to be realized (Kiru, 2018 at 4). In addition to WGWD, other stake holders, including men, should be involved in the education drives, as a way of creating awareness and bringing change.

We also need to take into account the mode of transmission of the content for each learning session (London & Baldwin-Ragaven, 2008 at 13). To promote effective communication, debaters should break down complex material. They should also avoid technical language. Information should be easy to access and packaged into simple, plain language. Pictorials – maps, charts, photographs, figures and graphs – can be used to support the goal of effective communication. The special needs of the blind community must also be considered. Consistent with the Constitution, and in order to reach a wider audience, local languages should be used.[67] All disabilities

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[66] Article 59(2) of Kenya's Constitution.

[67] Articles 7, 44 and 50(3) of the Constitution.

must be accommodated in these information-sharing sessions. Otherwise, these processes could end up being discriminatory.

Unlike judicial processes, which are adversarial or aggressive and formal, HRE tends to be accommodating and informal. The learning process can take place in any setting – academic venues, social gatherings, health centers, seminar or conference rooms, religious settings, via radio or television, among other forums. Distinct from litigation, which tends to be expensive, the costs of these sessions can be managed, especially if the instruction occurs as part of an on-going event or activity. The fact that the discussions take place in less formal settings is an additional advantage. This environment can encourage participants to speak freely, compared with a more formal setting such as a court room (Bajaj, 2012 at 125). Because they are run by WGWD, there is a high chance that the audience will engage and retain the information, which is being transmitted.

Despite these benefits, a number of limitations are noticeable. Primarily, one can attack these learning sessions on the basis that their scope is limited. One has to be in the particular setting in order to benefit from the lessons learnt. Unless the material in a particular sitting is recorded and transmitted, those who fail to attend will miss out on the information that was shared. Further, the lessons learnt can be easily forgotten, if they are not well stored or if a session fails to take into account the needs of all participants. Simply put, the information shared in these sessions should be available, accessible, and acceptable to all users. If these limitations are not addressed, the effectiveness of this intervention method will be severely curtailed.

Policy Interventions: An Additional Protection Layer

At policy level, Kenya, like many States in Africa, has several policy documents. Although some are general, others are specific to WGWD. These include the Vision 2030,[68] the Health Policy, 2014–2030,[69] the draft National Reproductive Health Policy[70] and the National Adolescent Sexual and Reproductive Health Policy.[71] There are also other guiding documents such as the National Guidelines on Management of Sexual Violence, 2014, the National Guidelines for Quality Obstetrics and Perinatal Care, 2012, and the Ministry of Health Revised Post Abortion Care Training Package. Collectively, these seek to address, among others, issues of SRHR of WGWD. They establish set criteria, which mirrors the legal obligations set by the

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[68] Available at https://vision2030.go.ke/about-vision-2030/ (Accessed: 2 April 2021).

[69] Available at http://publications.universalhealth2030.org/uploads/kenya_health_policy_2014_to_2030.pdf (Accessed: 2 April 2021).

[70] https://healtheducationresources.unesco.org/sites/default/files/resources/kenya_National_Reproductive_Helath_Policy_booklet_2007.pdf (Accessed: 2 April 2021).

[71] See https://www.popcouncil.org/uploads/pdfs/2015STEPUP_KenyaNationalAdolSRHPolicy.pdf (Accessed: 2 April 2021).

statutes evaluated above. Any aggrieved person can use these standards, too, to gauge the level of compliance by the relevant duty bearer.

Thus far, the country lacks a specific policy for WGWD. This is a huge gap in the enforcement regime. It is thus imperative for the Health Ministry, in conjunction with the Council and other interested parties, to come up with an appropriate guideline. The overall objective should be to protect the rights under consideration during these uncertain times. This document can complement the two enforcement strategies evaluated above. Issues surrounding the allocation of resources for SRHR for WGWD should be comprehensively covered by this protocol. The UHC agenda can reinforce this policy framework by containing within its essential services package the provision of sexual and reproductive health services to, among others, WGWD. Questions relating to the financing of non-medical costs (for example, transportation costs and costs of hiring carers) for WGWD must also be addressed, if the policy is to deliver. As the preceding discussion has demonstrated, these costs have continued to prohibit WGWD from accessing health care services, especially during this COVID-19 season. In order to address the particular needs of the target population, the regulations must take into account the intersecting factors that accompany the SRHR of WGWD, including the levels of poverty and illiteracy, their health status as well as age, gender, and sexual orientation.

Consistent with article 10 of the Constitution, the government also needs to put in place health resource tracking mechanisms to enhance the accountability of any resources that are channeled toward the enhancement of SRHR of WGWD. This tool can bolster M&E exercises. It can also promote effective and efficient utilization of resources. Collectively, these initiatives will contribute a great deal toward fulfilling the rights owed to WGWD.

Conclusion: Beyond the Rhetoric

In the 1927 United States case of *Buck v Bell, Superintendent*,[72] Justice Holmes of the Supreme Court held that a piece of legislation, which permitted the forced sterilization of persons with mental disability, did not violate the equal protection and due process clauses of the Constitution.[73] Today this view is unsustainable. WGWD are entitled to all the fundamental human rights and freedoms accorded to all human beings. The lofty commitments that governments make regarding the SRHR of WGWD need to be translated into actual entitlements. Although countries like Kenya are on the right track by putting in place constitutional, regulatory, and policy frameworks, as well as having a progressive judiciary, these fundamental

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[72] *274 US 200* (1927).

[73] According to the Judge, ‘It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind’ (at 207).

rights are yet to be fully realized. This chapter has flagged some of the difficulties that WGWD face.

In Kenya, article 186 of the Constitution, read together with the fourth schedule, demarcates the role of national and county governments. Although the former is responsible for policy making, the latter is charged with the responsibility of delivering health services across the country. This means that strategies that are aimed at addressing SRHR need to be implemented by the county governments. The resources required to meet this obligation come from the national government to the counties. This framework presents several problems. Primarily, it has been plagued by serious delays. Additionally, in some instances, the national Government has purported to perform some roles that fall within the mandate of county governments. This trend has to stop. The mandate of county governments should be respected and strengthened. Otherwise, how will they effectively deliver on the health rights of WGWD? As mentioned above, donor funding is unreliable. Hence, new resource streams must also be explored by Government and justice defenders. Local sources must be tapped into. These will contribute immensely toward plugging the current resource gaps.

Data on WGWD are also crucial. In addition to identifying and establishing their numbers, these statistics are crucial for planning purposes, especially in the current pandemic. As mentioned earlier, official statistics estimated that, as of December 2019, WGWD constituted 1.3% of Kenya's total population. According to the World Health Organization, about 15% of any given population are PWDS.[74] Women and girls constitute just over half of Kenya's population. Consequently, this renders the data on WGWD somewhat questionable. One would have expected their population to be significantly higher. The current state of affairs affirms the assertion that PWDS are still somewhat lost and forgotten.[75] Failure to collect proper statistics sits uncomfortably with articles 45(1)(a) of the *Banjul Charter* and 31 of the *CRPD*. Like any other population, WGWD should be properly identified and counted.

The COVID-19 pandemic has created new challenges for WGWD. Consequently, stakeholders must come up with a new tool box to meet these difficulties. In terms of action points for implementation, investment in health projects must be made in a disability friendly infrastructure (e.g., adaptive medical examination beds or chairs) within health facilities, as well as the relevant medical equipment, commodities (such as contraceptives, etc.) and medication. It also important to ensure that there is an adequate health workforce trained to deal with the unique vulnerabilities of WGWD during this time of crisis. Collectively, these initiatives will contribute immensely to their enjoyment of SRHR. Through this route, Kenya may inch closer to its commitment to achieving universal health coverage by 2022. Bearing in mind the discussion in this chapter, will this important milestone be reached as per schedule for WGWD?.

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[74] https://www.who.int/health-topics/disability#tab=tab_1 (Accessed: 10 April 2022).

[75] Laura Smith-Khan et al. (2014).

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Part XIV

Conclusion

Disability Advocacy in Uncertain Times: An Interview with José Viera

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José Viera and Peter Torres Fremlin

Contents

Abstract

This chapter brings you a conversation between Jose Viera and Peter Fremlin – two vehement and internationally influential disability advocates and activists. The conversation is an interview by Peter to capture Jose's view on how the disability movement can navigate uncertainty. Many thanks to Aliyah Esmail, Áine Kelly-Costello, Greta Gamberini, Elizabeth Lockwood, Stefan Tromel, and Nick Corby for making this interview possible.

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Introduction

Sometimes, it's easier to argue for inclusion while everything is going well. But in an economic downturn, or with other uncertainties, people might not be willing to try something new, or make an investment in inclusion.

This chapter brings you a conversation between Jose Viera and Peter Fremlin (a freelancer and disabled person working with international organizations to try to make the world a better place for disabled people). Their conversation aims to understand how we can continue to make change and get others to come with us in the disability movement.[1]

Jose has been at the heart of the international work that has brought governments and civil society together. In this interview, he shares the way he approaches advocacy and how he navigates the challenges the disability movement faces.

Highlights

One of the motivations for doing this interview is to get an inside view on how people are making change and how they understand the work that they do. Jose describes how his advocacy approach is closely tied to the way he understands the disability movement and our opportunities:

> I try to confront people with the reality in front of us. If you don't know what the reality is, how can you change it? Once we frame the conversation through bringing what the reality is, the next element is that you can be a partner to people with disabilities to change that reality. The element that I always like to share and not to convince people of, but at least to share, is that the reality that we are trying to change will bring better things for all.

This is the approach that ran through their conversation too: basing things in the context that we're in, making sure change is based on people's choice, and pointing toward the opportunities that are there.

Being able to understand both where we are and where we need to be makes Jose more interested in change as a process, rather than destination. Jose understands the disability movement as one that has grown out of people who looked for solutions to what limited them in their own lives, and then taken that forward:

> This lack of free decision making processes made us think that we need to be the leader of the change if we want to see something improved. That's why we didn't stop, or many of us didn't stop. We got what we went to the organizations looking for, and we took that flag and carried it out in different ways.

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[1] The original interview took place on November 21, 2022, and can be found here: https://www.disabilitydebrief.org/debrief/advocacy-in-turbulent-times/

As that journey implies, the disability movement is made up of grassroots organizations and activism, and those who took that flag forward deep into working with or inside establishment organizations. Sometimes, these different positions and perspectives can lead to tension within our movement, and Jose acknowledges this directly:

> We are part of a political movement with interests, different interests, money behind, power behind, reputation. Why wouldn't that be part of a social movement of a person with disabilities if that is part of the daily conversation of other movements? The fact that those tensions exist speaks to the fact that we are definitely creating something big or we are pushing for something important.

Jose argues that living in tension "is not a bad thing" but also that it can "make us better." It is especially important as we face an economic crisis that "will definitely impact the inclusion of persons with disabilities." Our movement is faced with two tasks simultaneously:

> We as the disability movement will have to play two games, from now on, and I would say for the next five or ten years. One is to create better opportunities, and the other is, at the same time, to ensure that what we've achieved doesn't get lost.

One of the familiar frustrations in advocacy on disability is the feeling that the movement has not gone far enough. Jose's point about the second game means that sometimes even staying put can be a victory, for defending where we are. Jose's message isn't that we should "sit back and relax and wait, but to be aware of the time that social change requires":

> Sometimes we are too hard on ourselves as activists wanting to change quickly. It makes sense because when you come from a world of denial, everything for you is urgent and you want it for yesterday.

This guidance for activists is also accompanied by the invitation that Jose makes for people to join in and share "the responsibility for positive change," especially to those of us who have been able to access opportunities to different resources. How do we start? Jose, as he promised, grounds it in the concrete:

> "Start with something that probably you need, that is close to you, is tangible and that you can see a change." . . .

Conversation in Full

"Everyone's Afraid of What's Going to Happen"

Peter: You've been traveling to Germany and Qatar and many other places trying to get governments and international organizations to pay attention to disability issues. How's it going?

Jose: We are living in such turbulent times. It doesn't really matter the region that you're in, everyone's afraid of what's going to happen. People are uncertain about the future. When you live in times of uncertainty, you try to reduce your exposure, to home again and be as safe as you can. In that context, I think the disability agenda can be affected.

At the same time, people want to have good news. The only thing that can push you forward is that you think there is a better future. By trying to include disability issues in different agendas, that can be good news for many. I'm not saying, of course, anything related to charity or social responsibility or corporate responsibility. But being more aware of the needs of others, like persons with disabilities, being conscious of the challenges that people are facing, can make you take different actions that bring good news.

That is my feeling. A lot of uncertainties, but a lot of hope and a lot of need for good news.

Showing People They Can Be Part of the Change

Peter: Your work deals with high-level policy and complex bureaucracies. How do you advocate with them?

Jose: There are still a lot of people that have different understanding of inclusion. Not the understanding where the person with disability is the center. What motivates me to talk to governments, to talk to high level officials, etcetera, is to show that they can be part of this change. They should be part of this change and that what we are talking about is possible. It's a matter of how we harmonize resources and political will to get that change that I'm talking about.

I try to confront people with the reality in front of us. If you don't know what the reality is, how can you change it? Once we frame the conversation through bringing what the reality is, the next element is that you can be a partner to people with disabilities to change that reality. The element that I always like to share and not to convince people of, but at least to share, is that the reality that we are trying to change will bring better things for all.

This can have different forms and shapes. Your language, your tone change according to who you have in the room because there are definitely differences among who is responsible, who is the most responsible, from social obligations to legal obligations, to whatever type of obligations. In the end, it's a matter of being willing to change the reality.

I avoid talking about my personal experience. I'm a bit skeptical of building the case for the movement from my own personal experience. I don't even know if my personal experience is reflective of the challenges that people with disabilities face.

I think my personal reality allows me to be clear on what is the reality of most of the people with disabilities. I always like to build a case from that concrete reality and invite people to be part of the change.

Choice as a Foundation for Change

Peter: Something running through your advocacy messages is the element of partnership and people's choice. Can you tell me more about how you see choice and agency?

Jose: I don't know if the right word is responsibility because I think that the connotation of responsibility sometimes can be turned negative. An opportunity to be part of the change. Beyond legal obligations, beyond political obligations, beyond financial obligations, there is always an opportunity to be part of a change.

I don't think that I would be doing what I do if I didn't believe that a change is needed. I know that the change that I have dreamed of will never happen. I'm just trying to get closer to that change or to the positive effects of the change.

I'm more interested in the change as process. Through being exposed to people who think differently, who do things differently also makes you think differently and interact differently. Keeping in mind that I have a good change to work for, but the process, the way, the path to change is equally enjoyable.

Of course the most extreme situation is if you are forced to live in an institution. But if you have to pay extra for your transport to go to meet with your friends because the local transport is not accessible, that is also a lack free choice. Of course, there's no comparison between being able to go to a party and what people with psychosocial disability experience living in institutions.

But in the end, the denial of free and autonomous choice, of decision-making, is what should make us all pursue change. To respond to your question, for me, change has a precondition of giving the chance to people to freely choose what they want to do. There is no possible change without the right to freedom.

A Common Root: Getting Support from Disability Organizations

Peter: It's interesting seeing the process of change as vital to us as the result. I guess it's partly because the process of change is of people realizing their choices, realizing their dreams, transforming themselves as individuals and as groups. You've struck on something that's a beautiful being part of the disability community, to be able to witness so many people doing that.

Jose: I see ourselves as a social movement. I think we started by trying to cover the absence of States [governments]. We all have the common root of going to disability organizations to get what we couldn't get from who was supposed to be responsible to provide services and support. We have been ambitious to transform that first connection with the disability movement into a political movement.

Peter: You mean transform these relationships that are supporting people in day-to-day lives into something that's much wider?

Jose: Yes and impactful. We come again to the right to choose, the right to freedom. This lack of free decision making processes made us think that we need to be the leader of the change if we want to see something improved. That's why we didn't stop, or many of us didn't stop. We got what we went to the organizations looking for, and we took that flag and carried it out in different ways.

Tensions in the Movement and Representation

Peter: I am glad you brought up the disability movement. Both you and I are in quite institutional parts of the disability sector. A lot of your work is deep into the establishment, with UN meetings, with governments. Do you see tensions between some of the institutions that are representing disabled people and that social movement side?

Jose: Saying that I don't see the tensions is basically ignoring part of the reality. I would say one of my developed skills is to be able to read quite effectively different realities. I do see tensions, and sometimes we perceive those tensions as barriers for us to work together. But actually I think that those tensions are part of the DNA of the disability movement as any other movement. Why should we be different from other movements?

Peter: What you mean by it being part of the DNA?

Jose: Living in tensions, coexisting with tensions. We are part of a political movement with interests, different interests, money behind, power behind, reputation. Why wouldn't that be part of a social movement of a person with disabilities if that is part of the daily conversation of other movements?

The fact that those tensions exist speaks to the fact that we are definitely creating something big or we are pushing for something important. One example is representation. Are the organizations that lead the conversation around persons with disabilities enough representative of the movement?

Peter: Good question, I was going to ask you that. Are they?

Jose: In my opinion, yes. But the tension in representation makes those who believe that the organizations that we currently have are representative [should] do our best to be representative: and that we don't claim to be representative by default. Those who do not believe that the existing organization infrastructure is representative of the movement, have the role of helping us to know what is not good enough, what is wrong.

Living in tension is not a bad thing. It's part of the movement, the reality, the process. It makes us better.

We Will Have to Play Two Games from Now On

Peter: Let's go back to how we started this conversation and reflecting on turbulent times. There's this very strong association between inclusion and resources that might play out in the economic crisis that the world is going through. It can lead to a step back in inclusion.

Jose: It's important to clarify. If inclusion was only about resources then inclusion wouldn't be as hot a topic as it is in many more advanced countries. Resources are needed to be more inclusive, but that's not enough.

Inclusion requires resources. Let's say it. Why do we have to say that if you're poor, but you have good will from your teachers, you will be included? No. You're going to be included in a different way or at the expense of the efforts of your family, for example.

The second thing to say is that inclusion is more than having resources available. With the use of technology we believe that inclusion is all about allocating more resources. But it's about the process again. It's about how we start and where we get to.

The economic crisis that we are experiencing and that we will experience more and more will definitely impact on the inclusion of persons with disabilities. We as the disability movement will have to play two games, from now on, and I would say for the next five or ten years. One is to create better opportunities, and the other is, at the same time, to ensure that what we've achieved doesn't get lost.

These two games require different skills and understanding of the reality. We need to continue expanding our frontiers but at the same time ensuring what we achieved does not get lost.

Peter: Unfortunately the experience in the UK over the past 10-15 years shows how important that second game is and how trying to respond to it can send you backwards in messaging. You have to talk about need and how badly we'll do if it's taken away. It can really take you off of rights.

Understanding the Progress that's Been Made

Peter: A lot of achievements on disability are at quite a high level and not necessarily reaching the lives of people with disabilities. How do you reflect on the different levels change has happened on?

Jose: If you look at the change from a holistic point of view, there has been a lot of progress. You can see it in many countries, many of the organizations that are fighting for the rights of people with disabilities are now better equipped to advocate for inclusion and at the same time many of those organizations provide basic services that otherwise we will not have access to.

Change takes time. The urgency that we see and that we have been talking about on this call makes us always anxious and feel that we are behind on things. If you see this from a holistic point of view, things that are currently impacting on persons with disabilities are possible because we discussed disability many years ago.

I'm not saying we should sit back and relax and wait, but to be aware of the time that social change requires. I don't think that is by accident that the Convention [on Rights of Persons with Disabilities] has the concept of progressive realization. We cannot be worse than we were before. For many of us, we started so low that any little improvement should be seen as the roadmap for improvement, for progress.

What is concerning, is that you and I cannot talk in five years' time and keep talking about the same things and concluding that no progress have been made. That's why I was telling you about these two games that we have to play in these turbulent times.

Peter: You're saying we need to get better at seeing the progress and sometimes the progress in terms of that second game is about defending what we have won. You can be in the same place and you've won many battles because you've defended where you were.

"We Need to Perceive Ourselves as Constantly Moving"

Peter: I think a lot of what you're saying is inviting us to be clearer those tensions and to avoid getting too frustrated by them.

Jose: We need to perceive ourselves as constantly moving and probably Peter, you and I are talking from the comfort of our house and with basic needs fulfilled, and I'm sorry if that doesn't describe your situation. However, I would like to have more things to be more included. Of course, they are different from the needs of children in Argentina.

We need to focus on what we see as progress. What is changing, what is moving, what is improving? Sometimes we are too hard on ourselves as activists wanting to change quickly. It makes sense because when you come from a world of denial, everything for you is urgent and you want it for yesterday.

A good example of what I'm saying is that the fact that we are discussing representation is already a symptom of progress. If we were not smart enough to make the movement grow to the level that it has grown, we would potentially be talking about anything else but representation. The fact that we are now fighting to access resources, positively fighting, constructively fighting to claim who is more representative, who is more effective, would the change be bottom-top, or top-bottom, etc. It's an example of the progress made.

Sharing the Responsibility for Change

Peter: I appreciate this chance to reflect together. To close out, Jose, what are final reflections that you'd like to share?

Jose: First of all, thank you for the interview. I really appreciate it.

I am by nature a positive person, and I would like to clarify that as positive, but responsible. I am not naive to say that that change will happen without me pushing for it. I think anybody who has decided to be an activist has the DNA to not feel comfortable in the situation that we are in.

I would like me to be more comfortable and comfort here means inclusion. At the same time, I see my brothers and sisters with disabilities even further out from what I think should be a minimum level of inclusion. This makes me be positive, but responsible for the change.

I would like to share that responsibility with others. The more we share that positive responsibility to promote change, the more effective we will be. You cannot expect that a mother of a five year old child who cannot access education will be an advocate. It’s already too much that she has to deal with.

There is another part of the movement, people that have experienced that and have the chance to live a different experience and have opportunity to access different resources. Those are the ones that have to be more positive, responsible for the change.

“Start with Something Small, Close to You”

Peter: Many people would agree with you, but they might not see how they can contribute to change. Is there any message you would share if someone feels that way?

Jose: I don’t know, and I don’t know if anybody will know what is the best way to start. My answer would be to start with something small, close to you and tangible.

My first experience with an organization of a person with disabilities was when I wanted to read a book, not even recorded by my mother, by someone else. My mom had to record the textbooks for the school. How can I ask her, on top of everything to read literature. I went to the local library and I said, "I want a book," and they said, "There’s no book. Let’s do something." I didn’t start it. I met with people who had started to record books for blind people.

Start with something that probably you need, that is close to you, is tangible and that you can see a change.

Peter: That’s a beautiful way to wrap up, Jose.

Jose: Thank you very much, Peter. Interviews are part of the advocacy.

Conclusion: Moving Forward

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Ezra Zubrow and Alexis Buettgen

Contents

Abstract

This final chapter of the *Handbook of Disability: Critical Thought and Social Change* captures the central ideas contained within this volume of work. We highlight the challenges and barriers that impede the progressive realization of human rights and disability justice and outline how this book envisions a sort of "normative paradigm," not in a positivist sense, but whereby disability is the norm. This paradigm is inherently critical of present social arrangements and translates reasoning into practical measures. The presence of disability is no longer an exception or rarity but a commonly accepted characteristic of the population. We describe how all the authors of this handbook embed their work in the social, human rights, and/or disability justice models of disability while noting that there is a need for ongoing paradigmatic development. We conclude with an invitation for utopian thinking, practice, and activism based on a collective vision for the future. A way in which to further the dialectical argument and paradigm shifts that reflect our current and future situations, conditions, environments, and forms of living.

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Introduction

This book is about transformational change. It is about changing the way institutions, media, government, communities, and individuals view and engage with disability. This is not a minor issue because – in the words of Colin Barnes – "disability is not a minority issue." People with disabilities comprise a large portion of our population, and many of us will experience disability in one form or another over the course of our lives – either directly or indirectly with those we love. Yet this critical mass of people is minoritized, minimized, dismissed, persecuted, oppressed, harmed, and given much less power and priority than they rightly deserve.

In line with the disability movement, we strive for transformative action to change systems and their underlying values and assumptions, with a focus on the redistribution of power relations and the elimination of oppression. This is different from the more commonly accepted and visible incremental or ameliorative actions we have mostly witnessed. With only a few exceptions, ameliorative interventions have been implemented with small strategic improvements or adjustments that generally secure continuation of the status quo into the future. We must be suspicious of ameliorative and technological fixes to the problems facing people with disabilities and critically look at who profits from these fixes, as well as who is included in the design, development, implementation, and evaluation of solutions and who is still missing.

This book explores these challenges from various disciplines and geographic and social locations. It identifies the visible and hidden barriers entrenched in our ableist societies. It traces the history of the myths, misconceptions, attitudes, laws, policies, practices, and portrayals of disability over the ages. It makes us cognizant of systemic forms of colonialism, imperialism, neoliberalism, fascism, sexism, racism, etc.

This book also provides us with hope.

Here, we define hope not as a call for cheerful optimism nor a denial of the urgent issues we collectively face but as wise and realistic hope. We embrace materialist insights that acknowledge how historical developments are created and constrained by concrete, existing material conditions. We believe that knowledge about these conditions is a form of power that justifies and amplifies hope. Ernst Bloch (1995) describes hope as a process that captures the moment of potentiality surpassing into actuality which opens up opportunities for interventions of active engagement and decision-making. According to Bloch, the right way to relate to these opportunities is through an active approach toward real tendencies with the goal to realize them. This approach is not merely a subjective combination of desires and beliefs but rather a reflection of metaphysical possibilities in the world. In a sense, this form of hope is reflected in the convention on the rights of persons with disabilities (CRPD) as a guiding framework for transformative change.

There have been numerous successes that have resulted from the field of critical disability studies, advocacy, and activism. These include the aforementioned CRPD, SDGs, national laws on disability, etc. Perhaps most importantly has been the CRPD. Although not perfect, this international treaty has been a template for national and subnational laws and continues to be an aspirational goal for groups and individuals with disabilities. With a strong focus on the implementation and monitoring of the CRPD, we are living in Bloch's described moment of potentiality surpassing into actuality.

One of the areas that Marcia Rioux was most interested in – and most effective at – was the process by which people with disabilities who had essentially accepted their fate of social exclusion could become advocates for change for themselves and for others. It was part of the underlying ideology that she and Bengt Lindqvist used in creating Disability Rights Promotion International (DRPI). They cocreated a training program, methodology, and mechanisms whereby disabled people themselves could learn about and monitor their experiences and violations of human rights. The DRPI initiative inspired hundreds of advocates first reporting on their experiences and violations of human rights and then taking political action at the local and national level and on the international stage at the UN.

This book is based on a belief that knowledge is power and a process that can be used for many purposes. Knowledge can be used to increase the gap between the rich and the poor or unleash the creative potential of every human being. As such, knowledge is a powerful resource (Laszlo & Laszlo, 2002). We believe it is up to those with access to knowledge to decide how to use that power. It can be used as power over others so that only an elite few can enjoy indulgent lifestyles or power to empower others to engage in meaningful and sustainable forms of social organization.

Stakeholders with various interests have created the ultimate form of the North-South interface relying on colonialism, imperialism, capitalism, globalization, foreign policy, diplomacy and international aid, mass migration, and disaster relief. The issue of disability, and disability studies and activism, has seeped through these countless channels and is hugely influenced by technological innovations such as the Internet. Virtual communication has configured disability policy and activism in unique ways, which has been explored in several compositions in this volume.

Current issues of intersectionality, increasing inequality, climate change, migration, and AI are pushing the boundaries of the CRPD and present new risks, challenges, and opportunities for transformative change. As noted by the contributors to this book, intersectionality has sometimes been taken up uncritically or co-opted in contemporary scholarship to limit the essentialized understanding of identity (Erevelles & Morrow). The rate of poverty and economic exclusion of people with disabilities is stubbornly high (Tromel). People with disabilities are chronically ignored in addressing issues related to climate change and migration and associated increases in emergencies and conflict situations (Crock & McCallum). The development of the study of the human genome and neurotechnologies is giving rise to ethical and legal dilemmas with increasing capacities for genetic manipulation, to intervene in the brain to enhance its state, erase fragments of memory, prevent behaviors, etc. (Bariffi & Quinn). The proliferation of AI is a mirror to our societal perspectives wrought with biases, exclusions, and neoliberal ideologies. As Treviranus aptly points out:

> The proliferation of artificial intelligence relying on statistical reasoning to guide and make decisions amplifies, accelerates, and automates these discriminatory patterns (Gupta & Treviranus, 2022; Treviranus, 2022). AI automation removes the option to make exceptions. Mechanizing decisions such as hiring, academic admission, loans, medical triage, urban planning, security, probation among other critical decisions exonerates the implementers of

> the harm these decisions do to outliers and marginalized minorities. One positive side effect of AI is that AI makes manifest the potential harms, such that these harms gain the attention of hard scientists and cannot be dismissed as unempirical soft science.

The third decade of the twentieth century is being claimed to be transformative of human society. In fact, the rise of artificial intelligence is compared to the introduction of the printing press or the introduction of the internal combustion engine. So we asked an artificial intelligence chatbot about the future of people with disabilities. The response we got was the following:

> There is a growing awareness and understanding about the needs and rights of people with disabilities, and this is leading to increased opportunities and advancements in technology, accessibility, and inclusion. While there are still challenges that need to be addressed, such as ableism, discrimination, and lack of resources, progress is being made towards a more inclusive society.
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> In terms of specific areas, employment opportunities for people with disabilities are expanding, with more companies recognizing the benefits of having a diverse workforce. Education and training programs are also becoming more accessible, allowing individuals with disabilities to acquire the skills and knowledge needed to succeed in various fields.
>
> Additionally, there has been a push for greater accessibility in public spaces and transportation, as well as advancements in assistive technologies and medical treatments. All of these developments suggest a hopeful future for people with disabilities, where they can live independently, participate fully in society, and achieve their goals.

This response reflects both a narrative of optimism and biases toward viewing people as valued according to their educational and employment status. It presents a partial truth in terms of accessibility and inclusion and yet also picks up the medical model as a persistently stubborn paradigm for the way in which we think and act toward disability. The growing awareness and understanding about the needs and rights of people with disabilities is true – and worth noting for the sake of hope – in some parts of the world. It is a goal, a dream, and a vision for others.

This handbook touches on these emerging issues and to us reflect the grand challenges for the disability movement. Disability art and literature are – to various extents – operating outside the boundaries of capitalism and neoliberalism which provoke the criticality of disability and are discussed throughout the many chapters of this text.

We are living in turbulent times, and people are uncertain about the future. Many governments, organizations, and individual activists argue that we need a collective response and collective action to address the multiple and intertwined social, economic, and environmental crises of our time. It requires wealthy nations of the Global North to take more responsibility for the implications of their actions on the Global South and move away from individualist and nationalist ways of thinking and living.

So what does the future hold? The disability rights model is growing and clearly the disability justice paradigm will become more prominent. What does it mean to achieve disability justice? What will be the characteristics of a new model beyond disability justice?

This book begins to envision a sort of “normative paradigm,” not in a positivist sense, but whereby disability is the norm. This paradigm is inherently critical of present social arrangements and translates reasoning into practical measures. The presence of disability is no longer an exception or rarity but a commonly accepted characteristic of the population. Disability would be widely considered to be a fundamental and natural part of human diversity. Disability would no longer be considered a condition associated with disadvantage and discrimination. The goal would be to create an inclusive and equitable society that values and supports all individuals, regardless of their abilities and where their productivity does not determine their worth. People with disabilities have firmly claimed spaces of power. This is where social, spatial, political, economic, and climate justice meet. It is both practically and theoretically useful in the realization of sustainable change.

This paradigm does not accept the status quo but seeks to change it. This paradigm exists in the imaginations of activists, advocates, and scholars. It is not just the reduction but the elimination of oppression, poverty, violence, discrimination, and marginalization of people with disabilities.

All the authors of this handbook embed their work in the social, human rights, and/or disability justice models of disability while noting that there is a need for ongoing paradigmatic development. The paradigm they describe is:

- Rooted in diverse written, oral, visual, and archaeological knowledges of disability history led by those outside the Western (particularly Anglo-Saxon) context
- A refusal and reconciliation of the epistemic and overt erasure of people with disabilities
- Informed by the values and principles of inclusive research, Black feminist conceptualizations of intersectionality, and indigenous ways of knowing and being
- Facilitated by epistemic collaboration for disruptive knowledge production as a strategy to foreground, critique, and challenge the hegemony of the many forms of structural oppression
- Enacted through “reciprocal relationships of learning, being, belonging, doing and becoming” (Lorenzo introduction)
- Driven by the politics of difference and inclusive design that eliminates the need for accommodations and adaptations for people with disabilities

This imagined paradigm focuses on translating ideas into practice and putting ideas to work with adaptability and flexibility and responsiveness to the particularities of temporal, geographical, environmental, political, cultural, and social context. We must also recognize the self, feelings, and emotional truths experienced by individuals. In this way, we appreciate a post-normative critique that avoids being dismissive of experiences and aims to find a way to enable the articulation of the gap between the “is” and the “ought” (Illouz, 2018). What is beautiful about a post-normative critique – and what aligns with the idea of disability as the norm – is that people would be free to be their authentic selves, free from the social constructions imposed upon them, and free from what others think and tell them that they “ought” to be. “A post-normative critique of emotional authenticity then has no fixed a priori normative position. . .it wants to abolish the distinction between subject and objects. . .it uses immanence as a tool to unsettle cultural hierarchies” (Illouz, 2018, p. 209).

The handbook emphasizes that thinking about and understanding disability and responses to body/mind differences drive change in advocacy, activism, practice, policy, and law. Our collective group of authors highlight the need for conscientization and challenge the ways in which the existing institutional order of the world's economy generates inequalities and poverty and underlies current international human rights and development mechanisms.

This is, of course, an incomplete discussion of the future of disability. Indeed, it is not intended to be complete. There already are signs of the development of a post-normative critique. One of the principles of this post-normative view is that people are free to be their authentic selves without being admonished by a critic who stands on an Olympic Mountain (Illouz, 2018; Walzer, 2002). A post-normative critique embraces ambivalence and emotional authenticity, moving away from socially imposed constructions of the self and of communities. We similarly embrace ambivalence with deep respect and appreciation for the complexity of disability and diversity.

Finally, this book is an invitation for utopian thinking, practice, and activism based on a collective vision for the future. A way in which to further the dialectical argument and paradigm shifts that reflect our current and future situations, conditions, environments, and forms of living.

In conclusion, the coeditors are optimists for the future. We believe that there will be a new paradigm that will combine with recent paradigms in other sectors of society such as employment, law, domestic and international policy, etc., to work on the grand challenges of our time. We must work together as a human species, with (rather than subordination of) other species, microbial populations, and water systems.

With that in mind, we thank you for your time and attention to the *Handbook of Disability: Critical Thought and Social Change in a Globalizing World*, and we leave you with a poem written in honor of Marcia Rioux by Pavan Muntha, a vehement disability and climate justice activist and scholar from India.

Augmenting rhythms of nature
When I got the idea of narrating my experiences, I sat down to speak;
I could listen to the murmurs of entangled clouds;
a breeze walking all over my body, again there is a murmur rolling right over my head;
Just before lunch this afternoon,
I am asked to inspect a fallen tree,
Which blessed all of us with its fragrance for years:
So disturbed I am, a thought instantaneously came,
The thought of tree,
Hit by a thunderstorm just an year ago,
On that deadly night it almost fallen on me.

But, I now realize, that tree saved me;
which stood out for years,
She was endlessly tall,
And wide with splendid branches,
Her canopy gave shade to windy corridors of life,
She was always a big host, for honey bees, squirrels,
Monitor lizards and red jungle fowl,
All of them are always,
chased relentlessly by kittens and monkeys;

She was a launching pad for monkeys,
To jump on the tiled roof from south-west:
Her white flowers with petals pink on borders,
Bedded the soil under her canopy,
Stretched all around her trunk,
Topsoil were soft under her,
splendid branches,
flowers, leaves, bark and fallen branches,
Offering food to microbes and insects;
A layer of humus is created,
hosting ants and other insects,
To energise them with cookies and nectar with special fragrance;
Hidden in the tissue barrels of flowers,
We often taste them but, with Ant bites on lips,
what a seductive host!

It was ruthlessly chopped off, a month ago,
But, now I see thousands of her children,
Covering the topsoil with a green carpet of saplings.

Can I augment these rhythms in the performing art of nature?
Mastan Vali, a seven-year-old brown tomcat,
Acquired his name after a young mountaineer,
Majestically walked into the dining hall with the demands,
Not just for food, also for cleaning of his left ear,
which he cannot clean by himself;
He lost Control over one of his back legs,
As a result of nails like teeth,
Of a pack of wild dogs,
Forced into his back spine;
He was given steroids to infuse strength,
He spent a few days in pain,
Recovered and joined the play of healing nature:
In a matter of weeks, he became the tiger, His Majesty!
But this time he is highly vigilant,
He started taming dogs, the class enemies;
During one of his battles, he killed a wild cat,
Who was much bigger than him;
His Majesty! Respected for his valour and wisdom;
He is a very responsible father,
He provides accommodation to all his lovers and their children,
He protects and nurtures them;
Sometime ago he was training his children to climb a tree,
Following the father, children also climbed the tree with three legs;
What an adaptation of skill?

Is this not mimicking of nature?

All of them are our co-travellers,
Teaching us diverse skills embedded in nature;
Chasing survival, day in and day out in the wild,
Skills are not about the number of limbs,
But our sense perceptions alone,
mother nature provides places for us,

No question of looking back and never think of any compromise;
Mastan, the hero of mountaineering, succumbed to the weather conditions;
At times our valour in the wild,
Take sides on the tipping point,
Our illusions play a role of judging mother nature,
Human knowledge works in ideal conditions,
When speculation transgresses the transcript of calendars:
Three, two or four, limbs doesn't matter,
Mastan, the two-legged animal,
And the tomcat named after him,
Are part of nature's circular economy;
They are redefining the performing art of nature,
Both of them are warriors of our times,
Each of Nature's judgement is towards regeneration and matter before admitting to nature;
Can I augment the rhythms in the performing art of nature?

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