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Research
Report

Hierarchies of power:

Disability theories and models
and their implications for violence
against, and abuse, neglect,
and exploitation of, people
with disability

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Introduction

The rise of the disability rights movement in the latter half of the twentieth century was a political and theoretical advance. Activists and scholars developed new ways of thinking about disability to support their demand for social change; the best known being the distinction between the medical and social models of disability. Despite its ongoing significance, the social model is not without its limitations, and in the decades since its formulation, scholars and activists have continued to theorise disability and its meanings. This theorisation has also extended to thinking about notions of ableism. The identification of paternalism is central to these theoretical developments, since disability often involves disempowerment and a loss of autonomy. Power imbalances increase the possibility of violence against, and abuse, neglect, and exploitation of, people with disability.[1]

This paper has been written for the Australian Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability to provide an overview of disability theories and models. It shows how these theories can contribute to the promotion of a more inclusive society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation.[2] It uses the lens of power to consider outdated and rejected ways of thinking about disability that are still pervasive and impact negatively on the treatment of people today (the charity and medical models of disability). Thereafter it explores models and theories that have been used by people with disability and their advocates to transform attitudes, systems, and policy so as to empower individuals to resist violence, maximise independence, and flourish on their own terms.

Preliminary definitions

While a key focus of this paper is exploring the meaning of disability, there is value in clarifying what is meant by 'theory' and 'model' in disability studies. In general, the former references broader theoretical methods and concepts that are applied in the context of disability (such as Marxism and feminism), while the latter represents prominent thinking about the nature of disability. Disability theorists have thus identified, analysed, and proposed models operating to shape the lives of people with disability. The analysis that

follows classifies alternative models and theories as an aid to understanding theoretical developments in disability. But in practice, the boundaries between each of these models and theories are fuzzy. The point is not to focus on or to debate taxonomies, but to see how the emphasis of each continues to shape the meanings of disability, and provide insight into social systems of power and violence.

Defining violence, abuse, neglect and exploitation is important and complex. Feminist theorists argue that the labels we give to behaviour can normalise it, so that definitions of violence have political significance.[3] The focus of this paper is outlining theories and models of disability, such that a detailed analysis of the nature and meaning of the terms violence, abuse, neglect, and exploitation is beyond its scope.[4] The analysis that follows considers how theorists have understood such terms and labelled the maltreatment of people with disability.

The charity model of disability and welfare

Although the medical/social model distinction is the best known theoretical framework in disability studies today, an older complement to the medical perspective—the charity model—understands disability as tragedy to be ameliorated or erased by generous giving.[5] The charity model thus establishes disability as dependency. People with disability are traditionally presumed incapable of employment and other self-determinative activities. The figure of the disabled beggar is ubiquitous in most human societies; a tragic character, dependent on the charity of others but often feared as dirty and contagious, reviled as someone looking to get something for nothing.[6]

The English term 'charity' has its origins in mediaeval Christendom, and intends to reference generous love.[7] Disability advocates came to recognise the dark side of charity, underpinned by a constitutive sense of pity. Charity and pity are oppressive, because they play on fear, sustain the superiority of the benevolent, and make people with disability acutely aware their lesser status.[8] Generally, charity involves the rich and powerful acting upon the relatively powerless person with disability.[9] Too often, the institutional purposes of the charity become more important than people with disability, who are positioned only as an afterthought. During the latter half of the twentieth century, for example, cerebral palsy charities relied on Miss Australia pageants to raise more than

$87 million, ignoring protests by women with disability that such charities reinforce standards of beauty that entrench their inferiority.[10] Protesters have also challenged other charities that present people with disability as objects of pity to raise funds for segregated accommodation, sheltered workshops and special schools.[11]

In Australia, as elsewhere, private charity is complemented by systems of social welfare that include income and service support. Social welfare is motivated by compassionate distributive justice, and built on a social contract in which tax payers invest in welfare provision so that they too can be cared for in times of need. In practice, however, welfare too often bureaucratises compassion and care, and recipients come to be seen as lesser citizens, a burden on the state, and thereby subject to depersonalising forms of supervision and control.[12] In cultures suspicious of welfare recipients, people with disability and other intersecting disadvantages can be weighed down by unresponsive services and living at or below the poverty line, trapped in an interminable cycle of inequality.[13]

In modern economies, disability services are provided by a mix of government, NGO, and for-profit businesses in a competitive market-based environment aiming to increase efficiency. Some disability theorists argue that market-based systems privilege the middle class, but that many people, especially those with cognitive and psychosocial disability, as well as people with intersecting racial, class, gender, and geographical (rural) disadvantage, struggle to advocate for appropriate funding and navigate market systems.[14] Consider the example of the National Disability Insurance Scheme (NDIS) in Australia. Many people with disability and their associates are enjoying access to better quality and more flexible supports then they were under previous systems. Yet a recent review found that participants:

> are frustrated about delays and lack of transparency around how the National Disability Insurance Agency (NDIA) makes decisions, need more support to become efficient and effective consumers, think the scheme is too complex and difficult to navigate, and feel they are not recognised as experts in their disability and that NDIA staff do not understand disability or appreciate the challenges people with disability face as part of everyday life.[15]

Thus, as suggested by the charity model, a scheme with positive intentions is at risk of reinforcing the oppression and inferiority of some people with disability.

Whether government oriented or market-based, religious or secular NGOs, or private businesses, the overwhelming majority of disability services are operated by people without disability who are engaged in well-meaning charitable work on behalf of the dispossessed.[16] Government has been decentralised, but people with disability are still understood as dependent, and our kept under the control of dispersed authorities.[17] The problem is not welfare and service provision per se, but that paternalistic presumptions of charity and pity still prevail. Paternalism is the assumption that people with disabilities (as with colonised First Nations peoples) need to be healed, cared for, supported, or managed for their own good—despite their individual will—and even though their present plight may itself be a product of violent intervention and control. 'Paternalism is often subtle in that it casts the oppressor as benign, as protector,'[18] and enables people in power to express sincere sympathy for people with disability while keeping them socially and economically subordinate.

Without substantive changes to personal and cultural attitudes and values, the paternalism people with disability are subjected to throughout the course of their life sustains hierarchical power and makes them vulnerable to direct and systemic violence, abuse, neglect, and exploitation.[19] When some people prove ungovernable and out of control, the justice or mental health systems take over.[20] The rare virtue of humility is one of the values that might be learned by professionals with power over the lives of people with disability.[21] It would enable them to appreciate the limits of medicine's knowledge of disability and recognise that people with disability are experts in their own experiences and bodies (where body is understood holistically to reference the physical, intellectual, and psychological self).[22]

The nature and extent of this lived disability expertise will be shaped by opportunity, expectation and support. People with disability living within closed environments and deprived of exposure to peer role models, new technologies, and alternative ways of living can hone their lived expertise by support that broadens their horizons. In recent years there has been a reappraisal of competency frameworks related to equalities and diversity, which has seen the adoption by health and social care professionals of the

cultural humility practice paradigm. Cultural humility involves a commitment to redressing power imbalances in the patient-professional dynamic, developing 'non-paternalistic partnerships with communities on behalf of individuals and defined groups.'[23] In the context of disability, these partnerships can involve linkages between professionals and disability peer and advocacy groups that work together with individuals to maximise their power and autonomy in all areas of life.

People with disability do depend on services and welfare, as does every citizen at some point in life.[24] There is a need to move from understanding disability as dependency to affirming our universal interdependency and reframing the idea of vulnerability. We shall return to these matters later in this paper. Disability theorists critiquing welfare and the charitable model of disability argue for a cultural transformation that understands service provision as support and empowerment rather than charity. Co-production is the term used to describe the involvement of consumers in producing public health and social services and the shaping of legislation, policy development and research.[25] It rejects dependency and the idea that services should be delivered to passive users.[26] In the context of disability, co-production centres the importance of the lived expertise of people with disability and their wider networks, and requires service providers to share power and establish active and equal partnerships.[27] It brings the collective insight of disability into the transformation of services, and so overturns hierarchies of power. Practically, co-production involves including people with disability at all levels and locations of service delivery, especially in leadership roles,[28] and enacts the principle of 'nothing about us without us.'[29]

The medical model of disability and eugenics

The medical model coincides with and builds on the charity model. It identifies disability as an individual defect to be eliminated or cured. At its extreme, the elimination of people with disability became the primary aim of early twentieth century eugenics movement globally and in Australia, effected by sterilisation and the segregation of people with disability in closed institutions.[30] Although explicit eugenics practices came to an end with the Second World War, presumptions about the poor quality-of-life of people with disability judged 'defective' still justifies medical practices aimed at preventing or ending

the lives of persons with intellectual disability and other impairments—sometimes labelled by disability theorists and advocacy groups as new eugenics or neugenics.[31]

For all of the benefits of medicine, the medical model—seeing impairment as abnormality, a tragic problem to be fixed—establishes professional power and control over people with disability.[32] Medical and diagnostic classifications of disability, which involve identification of biological and functional divergences from the norm, are so central to our understandings and systems of managing disability that a half century of critique by social theory advocates has not shaken their primacy. Under the medical model, disability is an overarching label that incorporates classifications of many varieties. Some, such as blindness, are relatively stable through history, and others emerge, re-form, and sometimes disappear as diagnostic horizons shift with medical research and cultural changes. Some critics point to the growth of classifications of mental illness and disability to suggest that we are in danger of pathologising and medicalising life itself, as exemplified in the growth of the DSM manual which started out as a 50 page document that now runs to 300+ pages.[33]

Autism, for example, was first described in a scholarly paper in 1943, and it was not until 1980 that the category of 'infantile autism' was introduced to the *Diagnostic and Statistical Manual of Mental Disorders* ((DSM-III).[34] Since then, the DSM's descriptions of Autism Spectrum Disorder has undergone substantive revision, and though much has been learned, its biological and behavioural characteristics are complex and research is still in its early days.[35] While psychological professionals and parents look for strategies to cure or ameliorate the symptoms and challenging behaviours of children on the autism spectrum, many adults with autism reject their negative diagnostic label as a disorder.[36] The neurodiversity movement argues that educational and medicinal strategies employed by therapists and parents to treat the 'disorder' are too often a form of abuse.[37] The debate between psychologists, parents, and people with autism is complex and mediating positions are emerging. The neurodiversity movement is not against diagnosis and treatment but rejects the ways in which diagnosis provides health professionals and parents with preconceived ideas that sustain powerlessness and normalise treatments that in another context would be judged cruel. There is irony in the prevailing stigma that attends to a diagnosis of autism; people that are more likely to be the victims of violence

are assumed to be aggressive and uncontrollable, and these presumptions perpetuate a cycle of trauma and violence.[38]

The benefits of post-Enlightenment medicine seem so obvious that they go without saying, and people with disability are not questioning the contribution of medical science to their health and well-being per se. Even so, modern medicine is based around a crisis intervention model that has pathology as its focus, and by extension, processes of defining and classifying pathologies. These processes are an operation of power, as professionals use their knowledge to secure, normalise, and control their subject—in this case, the disabled body—who is depersonalised and disembodied in the process.[39] Classifying pathologies have also expanded beyond the clinic to the wider society and narrowed the field of what is considered 'normal', effectively pathologising difference.

It is also rarely admitted that a diagnosis for a disability can have positive and negative effects.[40] For a person with a mental health condition, for example, a diagnosis can facilitate treatments that provide relief from unwanted and limiting symptoms, but it might also be the basis for confinement.[41] Knowledge of a diagnosis can lead to discrimination in areas such as employment, access to credit and insurance, and approval to adopt or have fertility treatment.[42] Two people with schizophrenia might also understand their situation differently, one looking for cure and medical support, and another asserting that they are not ill, but are experiencing a different form of spiritual awakening (see the mad pride movement).[43]

Not every disability diagnosis is complex and controversial. But every diagnosis entails a shift in the balance of power that places people with disability within the sphere of influence of medical professionals, healthcare workers, administrators, and policymakers whose actions will shape their life thereafter, for better or worse. As with the charity model, paternalism is central to the medical model of disability. People with disability are too often 'captives of care',[44] contained in institutional residences, group homes, mental health care facilities, aged care facilities, prisons, foster care, and other service settings. In these environments they are often disempowered, controlled, restrained, and at risk of violence, abuse, neglect, and exploitation.

Paternalism in healthcare is at its most dangerous in non-consensual medical interventions. Sometimes labelled by critics as 'lawful medical violence', non-consensual interventions are justified as care because of the medicalisation and pathologisation of disabled bodies, behaviour, and life circumstances.[45] Women with disability are especially vulnerable to lawful medical violence, such as when they are subject to deprivation of sexual liberty, forced contraception, and forced sterilisation, rendering them effectively genderless and sexless, less than human.[46] In some widely discussed international cases, young girls with disability have been subject to sterilisation, breastbud removal, and growth attenuation therapy, practices legitimised by doctors, bioethicists, and lawyers for the sake of the child's safety, and the ease and intimacy of her care.[47] These extreme examples are symbols of everyday practices that are considered normal in many healthcare systems, such as the physical and chemical restraint of people with disability (and older people living in nursing homes).[48] They are a product of the 'medical gaze,' of professionals not merely passively interpreting bodily crisis, but actively pathologising difference to legitimise non-consensual violence that in another context would be unthinkable, often rendering its practices exempt from scrutiny.[49] Ironically, in the medical gaze—or in the context of disability, the stare—the person is rendered invisible, and all that is seen is the diagnosis, the problem, the 'grotesque spectacle' that needs to be eliminated, controlled, or kept out of view.[50]

When the difficulties attending to disability are perceived to be medical, they are solvable by increasing funding for research on cures and therapeutic interventions, rather than other more systemic reforms, such as removing barriers to employment, human rights protection, and other social transformations.[51] The medical model's focus diverts attention and resourcing away from building social and economic supports sorely needed by people with disability in the community.

The social model of disability

While the medical model locates the *problem* of disability with an individual's abnormality and functional limitations, the social model switches attention to the social organisation, asserting that disability arises because society is not shaped to include people with impairments and provide them with the opportunity to choose their own futures.[52] The social model distinguishes between individual impairment and disability,[53] asserting that

disability is the social exclusion imposed on top of impairment.[54] The model confronts the conventional wisdom of charity and medicine that disability is a personal tragedy, instead making it a matter of justice. It stresses that people with disability are excluded from full social participation by the inaccessibility of the built environment and social systems designed without taking their diverse functional requirements into account.

Credited as 'the big idea' of the disability rights movement, the social model of disability emerged from a polarised debate on how to achieve social reform between two activist organisations in the United Kingdom, concluding with a document called the *Fundamental Principles of Disability.* [55] Popularised and internationalised during the 1980s and 90s, the social model has had widespread influence on the self-understanding of people with disability, particularly in its challenge to internalised pathologisation and external pity and paternalism.[56] It has facilitated self and community advocacy, and birthed the discipline of disability studies. It also had a major influence on international policy, most notably on the *Convention on the Rights of Persons with Disabilities* (*CRPD*) (see the final section of this article for further comment).[57] In highlighting the barriers to social participation, the social model stimulated new ways of thinking about the social environment in which we live. This includes, for example, the ideal of universal design, which looks to shape the physical and social environment, not with the average or 'normal' person in mind, but to accommodate human diversity.[58] Universal designers seek to shape public spaces to enable access to people with diverse impairments, children, people who are temporarily and permanently ill, people from diverse cultural backgrounds, and the elderly—i.e. every person at some point in life.[59]

The social model seeks to redress systemic discrimination and empower people with disability. It looks to reform disability support systems, public policy, and the institutions and domains that frame human life from birth to death. In its earlier theoretical development, proponents tended to draw on Marxist and materialist views of history, arguing that industrial capitalism and individualism established the conditions in which people with impairments were unable to meet the demands of wage labour and were thus rendered useless and worthless, and removed from the support of families and local communities.[60] While the Marxist analysis is no longer prominent, the social model retains an emphasis on the importance of changing the economic and material conditions

of disablement. It intends to transform relations of power, increasing the agency of people with disability. As people are given power to choose and direct their own lives, they are better equipped to resist personal and systemic violence, and to shape their horizons according to their personal interests, values, and meanings.

Criticisms of the social model

Notwithstanding its achievements, there is substantive literature critiquing the weaknesses of the social model, although even its critics recognise its conceptual and political contribution to making the world more accessible.[61] The model's diminishment of the significance of the ever-changing body underlies the various criticisms levelled at it (an issue we discuss below as 'embodiment'). There is some irony in an ideal that purports to accommodate difference and diversity that diverts attention from bodily diversity and conflates disability into the shared experience of discrimination and social exclusion. Defining disability negatively and focusing on the social and political has the potential to underplay the unique joys and challenges of certain impairments. The social model cannot speak to the bodily aspects of our personal flourishing, and it ignores the bodily limitations and pains that many people with disability wish could be ameliorated, whether through medical treatment, technological advance, or social transformation. It is also silent about the co-constructive relationship of disability to ideas of abledness, or indeed the designation 'abled-bodied' wherein the idea of ability and citizenship has changed over time (see ableism below).[62]

The attempt to maintain the distinction between disability and impairment is artificial.[63] Under the social model, disability is negatively defined, as an injustice that should be removed,[64] but the achievements of the disability rights movement are also built on disability pride and identity, on the insistence that disability is a common part of life. Social proponents might respond that it is impairment not disability that should be common. But their tendency to distinguish impairment and disability (and largely ignore the latter) fails to recognise that our humanity is at once bodily and socially embedded. The social model forgets or underplays the fact that disability is always a complex interaction between the functioning of our bodies and the physical and social environments in which we live.

Consider the distinction between health inequality, which describes the measurable difference in health between people with and without disability, and health inequity, which is difference that is avoidable and unjust.[65] People with disability may experience health inequalities directly related to their impairment, which advances in medical and technological research and treatment can address. In addition to the consequences of their impairment, people with disability experience health inequity when they face barriers to accessing treatments and technologies that would improve their health outcomes. More broadly, they experience health disparities unrelated to their impairments which arise from social determinants; income, education, and social location have a dramatic impact on health outcomes.[66] The various causes of health inequality are enmeshed, bodily and social; not only or even primarily the latter, as strict adherence to the social model implies. Impairment is not generally a neutral characteristic, and impairment prevention and disability rights are not incompatible.[67]

That impairment is central to the experience of disability is a point that has been emphasised by feminists and disability scholars in the global south, who critique the masculine and western focus of social model theory (see below).[68] The social model is an attempt to universalise a definition of disability, but that is to disavow the variety of approaches to embodiment and social exclusion that emanate from outside of the West.[69]

Advocates and scholars committed to the social model respond to its critics by noting that its dichotomising of disability is pragmatic and political, a calculated overstatement intended to change people's thinking.[70] With some justification, they note that shifting the cause of disadvantage from impairment to social disablement has been the key to the disability rights movement's successes to date. They thus conclude that any softening of this stance puts at risk these successes and undermines the capacity to address continued injustice.[71] Yet, a model's rhetorical and political effectiveness is not a sufficient basis upon which to ground theoretical underpinnings, especially since there is no evidence that similar and broader social changes cannot be affected by conceptions of disability that embrace a more complex perspective.[72] The utility of a social theory is connected to its capacity to explain a social situation, and a partial explanation weakens its rhetorical power.

There is also no inherent link between the cause or outcome of disadvantage and the remedy for that disadvantage. Thus, on its own, the social model of disability cannot answer the question, 'what do we do now?'[73] A person with a spinal cord injury who uses a wheelchair will benefit from the implementation of legislation that ensures full access to public and private buildings and facilities, but they might also be given wheelchairs that can negotiate stairs, or in the not-too-distant future, enjoy a full or partial cure. The social model of disability, especially when principles of universal design are considered, reveals the value of non-staired access to social spaces, but that should not invalidate the latter two remedies, even though they are directed at the individual's impairment. After all, a wheelchair is a technological device intended to ameliorate loss of the function of being unable to walk. Persons who experience deafness can benefit from hearing aids and cochlear implants, although many in the Deaf community would prefer to create social settings where sign language is common, deafness is not disabling, and Deaf culture can be preserved.[74] But even if the social model focuses on the disablement that arises from lack of access to sign language, does that mean that cochlear implants or hearing aids should not be considered a valid and complimentary remedy? More broadly, recent disability scholarship has interacted with the cyborg/post-human discourse to examine the ethics and opportunities that imaginative technologies provide.[75] The distinction between cause and solution does not mean the social model is unimportant, just that it does not exhaust the ethical challenge of disability.

Cultural and critical theories

Social vs medical constructions of disability have their origins in Britain and Australia, with their social democratic welfare systems and placement of disability within health sciences and services. The social model has had global significance, but in the USA disability studies predominantly resides in the humanities. Because of the significance of the Civil Rights movements in US history, disability studies has emerged alongside the emancipatory scholarship of other minority identities, and thus it draws heavily on critical cultural theories and the identity politics of feminist, racial, and LGBTQI+ rights movements.[76] Cultural or minority identity theories understand disability, not as a negative consequence of socially constructed abnormality, but as a lens with which to critically examine the cultural assumptions that create and sustain embodied life and

systems and structures of power. Theorists contrast their understanding of disability from the social model by rejecting artificial binaries (medical/social) and emphasising embodied identity and the cultural framing of disability.

Cultural or critical theories are so named because they focus on the values, beliefs, norms, rationalisations, symbols, and ideologies that shape our way of life. Cultural theories of disability have a critical and constructive component, first unmasking the extent to which the meanings and values of normalising culture are biased by ableism and create and sustain power hierarchies, discrimination, alienation, and violence and, second, imagining new ways of thinking, and identifying symbols and narratives that welcome diverse embodiment and show people with disability as fully human in their strengths and weaknesses. In the modern world, cultural values are sustained and communicated by religions and sacred texts, political debate, literature, art, music, movies, television, games, and social media, and hence cultural theorists employ hermeneutical strategies and utilise disability as a lens to read and reimagine the cultural meanings of these various 'texts'.[77]

Ableism and abled privilege

Cultural disability theories unmask the prevalence and consequences of ableism, a term (used mainly in North America and Australia) that describes prevailing expectations about typical body abilities and the disablement and disadvantage people experience when their bodies and functioning capabilities are seen as abnormal. It is 'a trajectory of perfection' that functions to inaugurate and reify the norm.[78] Compulsory able-bodiedness is the assumed and unacknowledged normality shared by people without disability (and often internalised by people with disability).[79] It leads to an emphasis on sameness as the basis of equality.[80] Ableism produces an imagined standard that constitutes the essential and full humanity (the species typical body in science, the normative citizen in political theory), against which disability is a diminished state of being human.[81] Thus, it should be cured, ameliorated, or hidden away by whatever means are available. Ableism is another reference to power and its attendant violence, the hierarchy of the abled over and against the disabled. The related term, disablism (used primarily in Europe, and sometimes as synonym for ableism), has a more negative slant, paralleling sexism and racism, and

focuses on the disablement and disadvantage experienced when society is not structured to include people with disability.[82]

In the context of the global emergence of the Black Lives Matter movement, one way of thinking about ableism is to note its correspondence with white privilege. Whiteness refers to a dominant set of norms that are valued over others (such as appearance and language), which confers privilege individually and collectively on whites through institutional structures and (un)conscious actors.[83] Similarly, abled privilege maintains the power of the 'abled' through presumed norms and formal and informal structures and actions. [84] Values that establish the inferiority and powerlessness of people with disability (such as assumptions in civic planning that all citizens are normatively mobile, or by employers about the necessity of a 9-to-5, office bound, five day workweek) may be conscious or unconscious. Just as most white people claim not to be racist, so too are most people without disability unconscious of their abled privilege. As a result, it is largely invisible, even seemingly non-existent, which makes it much harder to combat.[85] It is maintained by abled people's rationalisations and their unwillingness to face up to the way their social advantage propagates unequal outcomes and hidden violence against people with disability.[86]

While emerging from cultural studies, ableism takes on its own theoretical horizons as the study of ablement. It seeks to move away from the typical dichotomy of abled/disabled, dispensing with the 'ghost of comparison' that too often underpins conceptions of the self (and theories of disability).[87] In recognising that both disability and ability are fluid moving targets, it gives up on the futile demarcation between abled and disabled by rejecting the ableist normal altogether, focusing instead on process and practice, on the specific conditions and systems that exclude and include, disempower and empower. Ableism is thus entangled with the intersectional and likewise fluid categories of sex, gender, race, class, and culture.[88] As a theoretical development, ableism makes the insight of disability scholarship applicable to broader academic disciplines that examine cultural values, practices, and processes.[89]

Embodiment

For many cultural theorists, embodiment is central to disability. Reference to embodiment is more than just an affirmation of the importance of bodies but speaks to the ways in which we know and experience the world as socially located bodies. Bodies and impairments change as our ageing flesh interacts with a rapidly changing globalised world, too often in ways that exacerbate impairment and social powerlessness.[90]

People with disability exist in their bodies by negotiating cultural attitudes and values that are often pathologising, disempowering, and dehumanising. However, they also contest those attitudes by envisaging and enacting new ways of thinking and living.[91] People whose bodily experience shapes their social position as outsiders can 'enjoy an epistemological privilege' that enables them to see society and its biases and ideologies differently from those with power and privilege.[92] It is this deep knowledge that grounds the importance of disability leadership and collaboration in any efforts to redress disadvantage, without which uninformed people in power merely perpetuate the violence of paternalistic systems.[93]

Where the medical model views society as irrelevant, the social model highlights the influence of social forces on impaired bodies. However, complex embodiment understands the disabled body and its social representation as being mutually defining and transformative.[94] Because this is so, the diversity of disabled bodies cannot be ignored in social theorising about disability, nor in its political actions. The diversity that arises from complex embodiment exists between people with different disabilities, experienced at different times in life, and located in different social environments. Complex embodiment is also fluid for the individual, changing throughout the course of life as their body and environment change together.

Cultural theorists generally emphasise the unique embodiment of every individual, and social model advocates treat disability as a single category. Both perspectives have good reason to be concerned about diagnoses that differentiate categories of disability, which can lead to presumptions of homogeneity and stigmatisation. Yet embodied disability can be understood as an affirmation of individual uniqueness and a recognition that particular types of disability embodiment share social experiences and needs. In the context of

intellectual disability, for example, its differentiation from the larger category of disability enables examination of the violence and marginalisation often experienced by people with intellectual impairment, and facilitates targeted education, health services, social support, and policy development.[95] At the same time, affirmation of unique embodiment acts as a resistance to stereotyping and stigma (see also intersectionality later in this paper).

Disabled and crip identity

Diverse embodiment does not preclude the possibility of the formation of a disabled identity. On the contrary, it is the very difference of disabled bodies from ableist norms that causes the shared experience of paternalism, prejudice, and bodily vulnerability that ground the disabled identity and give it its political motive and power.[96] This shared experience generates disability cultures, not based just on the negative awareness of oppression (on what others say about disability), but on an emerging history, art, music, literature, symbolism, and relatively unified worldview. While this worldview is difficult to pin down, it at least accepts human difference and vulnerability, tolerates ambiguity and unpredictability, finds humour in dire situations (even in oppression), is flexible and adaptive, and entails a commitment to establish communities that are shaped to enable full participation.[97] It is a proud and political identity that seeks to unmask ableism and transform the sociocultural environment to provide people with disability the power to resist violence, make choices about their own future, and thrive, not despite the pains and challenges of embodied disability, but with and through them.

It is noteworthy that person-first language common in social theory ('person with disability') implicitly takes disability as a negative construct. Cultural and identity theorists look to reclaim embodied disability as a mark of power and pride, and willingly use identity first language. The Australian disability activist Stella Young describes what this reclamation meant for her in a letter she wrote, not long before her death, to her imaginary eighty-year-old self:

> I stopped unconsciously apologising for taking up space. I'm sure you can scarcely imagine that now; a world were all disabled people, women in particular, are made to feel like we're not really entitled to inhabit public spaces. I started changing my

language. To jog your memory, back when you're still thirty there are all kinds of fights about whether we are allowed to say "disabled people" at all. It's "people with disabilities" that's all the rage. … But I've never had to say that I'm a person who is a woman, or a person who is Australian, or a person who knits. Somehow, we're supposed to buy this notion that if we use the term disabled too much, it might strip us of our personhood. But that shame has become attached to the notion of disability, it's not your shame. It took a while to learn that, so I hope you've never forgotten. I started calling myself a disabled woman, and a crip. A good thirteen years after seventeen-year-old me started saying crip, it still horrifies people. I do it because it's a word that makes me feel strong and powerful. It is a word other activists have used before me, and I use it to honour them.[98]

Young's claiming of disabled and crip identity has parallels to feminism and queer theory, taking the derisive 'crippled' and turning it into a label of power.[99] To claim the disabled identity or to come out crip is to own the impairments (the differences) that our culture tells us are shameful and wear them as a mark of pride. It uses the disruptive potential of disability to confront the compulsory able-bodiedess of normative culture, unmasking the narrow assumptions that create and sustain power, control, and exclusion.[100] It can seem paradoxical that the claim to individual uniqueness establishes a collective crip identity, but difference is judged against ableist norms, and identity is grounded in shared embodied social and political experiences and ideals.

Cultural and identity theorists note that disability is a category with blurred boundaries.[101] At what point does chronic illness become disability, or sensory loss become blindness or deafness? Since older people experience physical and social impairment and marginalisation, is old age disability? A person without disability today may find themselves disabled tomorrow. Blurred boundaries and the vulnerabilities of human life are what make the disability perspective universally relevant. Extending this logic, some theorists invite family, friends, and activists who do not themselves have an impairment but who live with those who do to claim crip as a means of endorsing the desirability of disability and challenging simplistic dualisms such as abled/disabled.[102] This invitation gives people without disability the opportunity to participate in its social and political mission, on the basis that 'it is not your disability status that matters most, but your

disability politics.'[103] Yet, while it is important to affirm disability as an open and fluid identity and encourage allies to share its goals, the problem with the suggested broadening of identity is not only that of appropriation and paternalism, but that, once again, the deep knowledge that comes with embodied disability is done away with.[104] Disability is more than just a choice and a label. At the least, it can be deployed strategically in an essentialised way to obtain access to goods, services and legal protections.[105]

Much more common than people without disability claiming crip is that people with disability reject the identity and label, an issue that is a primary concern of critics of cultural and identity theories.[106] There are many reasons for this rejection. 'Passing' occurs when there is a perceived cost or danger in disclosure, so that a person disavows disability, if they can, by hiding it, or otherwise by making light of its significance.[107] Given the prevailing negative attitudes to disability and the cost of disclosure, it is not surprising that people with disability choose to pass as nondisabled, but in doing so they find themselves caught between a rock and a hard place. Passing can be a product of internalised ableism, and resentment of one's own embodiment is self-destructive.[108] Even if chosen as a deliberate strategy to avoid disabling prejudice, it makes negotiating the social environment more difficult. A person with a mental health condition, for example, is likely to have good reason to pass as nondisabled in the workplace, but in doing so they also lose access to potential workplace adjustments and support. A person with hidden disability may have no opportunity to disclose, and will then be subject to public judgement and shaming about their functional incapacities and right to use accessible bathrooms, parking spaces, and other facilities. In such cases, 'coming out' as disabled can be away of discarding shame.[109] In the context of COVID 19 that dominates global horizons as I write this article, for their own safety, some people with disability are required to come out of the closet to employers.

There are other potential problems with framing disability as a minority identity. It has been suggested that basing identity on victimhood can generate 'a litany of oppression and woe' that ignores and potentially undermines the achievements of the disability rights movement to date, and reinforces negative attitudes within the disability community and in the wider public.[110] This critique, however, is not a reason to reject identity formation

but, rather, to ensure it has a broader framing, one that carries forward the powerful legacy of the disability rights movement, recognises the full humanity of people with disability, and values their place in the community. Even so, many people with disability will not want the label and reject the identity and, paradoxically, the freedom to choose how to define oneself satisfies the aim of both the social model and cultural and identity theories. The value of any theory of disability is not its universal acceptance, but its explanatory capacity and contribution to making a society in which people with disability and all vulnerable and marginalised people have increased agency.

Feminist disability theorising

Feminist disability theorists have emphasised the particularity of women's embodiment of disability. Even as disability rights came to prominence in the 1980s, women with disability were critical of the male control of the movement.[111] Seeking to elevate women's voices, they formed their own networks and advocacy bodies—such as Women with Disability Australia—and organised and advocated using feminist principles.[112]

As with other cultural theorists, feminist disability scholars are critical of the social model's failure to understand the importance of the impaired body on women's experiences of disability.[113] Feminist theorists examine cultural gender norms and sexual expectations and the ways they play out for disabled women. Most woman are subject to sexual objectification and thus treated as less than human, with the violence against them normalised and thought to be inevitable.[114] This objectification and dehumanisation is heightened for women with disability, for whom the male 'gaze' is often replaced by the 'stare', a gesture that judges the disabled person as freakish and vulnerable,[115] and that 'creates disability as an oppressive social relationship.'[116] Feminist disability theorists address cultural assumptions that sustain dehumanising cultures, critically examining stereotypical representations of women (and men) with disability, and look to recognise the diverse bodies of women with disability as beautiful and powerful.[117]

For women and girls with disability, sexism and ableism intersect to increase the likelihood that they will experience violence. Mirroring the situation globally, women with disability in Australia are three times more likely than women without disability to have experienced sexual violence within the last year, and more than 62% will have been

subject to violence since the age of 15.[118] Unmasking and addressing the problem of violence against women is central to feminist disability theory and advocacy.

Part of the challenge of this advocacy is there is no uniform definition of violence against women and girls, although it is generally conceptualised in the context of domestic, spousal, or family violence, involving physical violence, sexual assault, and psychological and emotional abuse and control, including isolation, humiliation, threats, and control of finances.[119] While domestic settings are relevant to many women and girls with disability, this limited framing excludes the institutional and service settings and relationships in which they frequently experience violence.[120] In these settings, women and girls often negotiate imbalances in power with staff and management, without adequate legislative and policy frameworks for preventing and responding to the violence and abuse they incur. Violence experienced in these settings is typically downplayed and detoxified, labelled 'as 'service incidents', or 'administrative infringements' or a 'workplace issue to be addressed', rather than viewed as violence or crimes.'[121] Degrading violence may also be justified on the grounds of 'managing behaviours'.

The dehumanisation of women with disability extends to presumptions about their incapacity to perform roles such as those of spouse and parent, which (as noted in response to the medical model) leads to forced sterilisation, segregation, and other violent and abusive practices.[122] The experience of dehumanisation has led some women with disability to have different perspectives to that of mainstream feminism and other rights advocates about policy topics such as prenatal testing and euthanasia.[123]

Intersectionality and disability theorising in the global south

Just as there is no single experience of disability, and no single experience of being a woman, sexism and ableism intersect with other dimensions of a person's identity.[124] Intersectionality speaks to the ways in which systems of power, including sex, gender, sexuality, race, class, caste, ability, and age intersect and overlap, shaping an individual's experience of the social world.[125] More than just a tool for analysing current and past inequality, intersectionality can ground collective action of those who have been marginalised, and become the basis for change in power relations.

Disability is often overlooked by intersectional theorists (who tend to focus on gender, race, and class), but there is strong evidence that people with disability are subject to multilayered hierarchies of disadvantage.[126] We are used to thinking about dualistic hierarchies such as ability/disability, but sociocultural relations of power are woven together in multifaceted intersecting relationships, so that the experience of a woman with disability who is also a First Nations person is both connected with and distinct from that of a woman without disability in her community, as it is with that of a nonindigenous woman with disability. The first Nations woman with disability is likely to experience some degree of marginalisation from both her culture and from others with disability, as well as connections to both identities that can be empowering.[127]

Impairment itself can be thought of as another layer of identity. Although often ignored by social model theorists, embodied disability means that the social world is experienced differently by people with dissimilar impairments, some of which tend to attract higher levels of prejudice, paternalism, stigma, and marginalisation.[128] Some people have multiple intersecting impairments. Every person with disability will have different challenges and opportunities embodied in their overlapping identities.

The diversity that emerges from intersectionality challenges the tendency of disability studies to focus on the perspectives of Western disability scholars. The majority of the world's people with disability live in the global south, and there is growing recognition of the need to give voice to their experiences and perspective.[129] Western imperialism had a devastating impact on cultures and economies throughout colonised nations. This violence continued through the wars of independence, and led to political crises and poverty that continues to affect communities through to the present day. Disability theorists draw on critical (post)colonial theory to label this colonising violence and attend to the 'social suffering' and impairment it has caused throughout the majority world. [130] Violence and poverty produces impairment, and in a vicious cycle, people with disability suffer the worst effects of poverty. Contrary to the social model, theorists thus recognise the importance of attending to the causes of impairment, and treat prevention of disability as a key issue.[131] Drawing on diverse cultural and religious traditions, they bring different ideas of the self, family, and wholeness to conceptions of disability (which inform the thinking of culturally and diverse people with disability living in Australia). It is beyond the

capacity of this paper to detail the diverse conceptions of disability emerging from this global scholarship.[132] We can, however, highlight indigenous theories of disability, particularly those of First Nations people in Australia.

First Nations people with disability

Colonial attitudes about the superiority of Europeans over First Nations people and the consequent massacres throughout Australia are well documented.[133] Invasion and the dispossession of land created the environment that drastically increased rates of disability among First Nations people.[134] Today, 38% of the First Nations population have disability, which is more than twice that of the nonindigenous population (18%).[135] 25% of First Nations people with disability will have experienced violence in the last 12 months.[136] The intersection between First Nations and disability disadvantage plays out in high rates of incarceration—the criminalisation of disability—and the continued scourge deaths in custody. [137]

The disabling impact of colonisation means that, for many First Nations people, the category of disability or impairment can be 'another marginalising identity,'[138] resonating strongly with ongoing violence, repression and stigmatisation. There is, therefore, resistance to accepting westernised and individualised concepts of impairment and disability, including the social model.[139] Although constructions vary, many First Nations languages do not have a word for disability. Many people classified with disability reject the category as antithetical to their beliefs and values, since within First Nations cultures, people with impairments are accepted and included as part of the diversity of society.[140] First Nations definitions of health are often framed around the capacity to participate in and contribute to the well-being of the community, so that impairment is not experienced as disabling unless it excludes a person from the communal and cultural life—a conception that parallels social model ideals.[141] Furthermore, many First Nations people place disability within a hierarchy of identity in which their disability is secondary to their cultural identity. Given the trauma that has come from colonising violence, collectively they can identify as 'a race of people that the government has disabled.'[142]

Recent work on the experiences of First Nations people with disability proposes a cultural model of disability inclusion, which sets aside emphasis on either impairment or disability

and instead focuses on individual and communal well-being by fostering active participation in community and cultural activities.[143] This proposal converges with the intent of the social model to look beyond the labelling and exclusion of people with impairments and emphasise inclusion, and mirrors some of the themes of cultural models in the aim to move past the medical/social dichotomy and embrace the power of culture. Its key distinction is its insistence on communal interdependence as the empowering motif. It is only in self-determination and the reclamation of culture that First Nations people with disability can be free from the colonising violence that they too frequently experience.

Theoretical reflections on interdependence

Interdependence and vulnerability

First Nation people's rejection of individualised concepts of disability raises similar questions to those addressed by disability theorists exploring issues surrounding personal autonomy. Western tradition, from Aristotle on, defined human nature by reference to intelligence and idealised the independent rational *man*, who delights to give but deplores asking for or receiving help, which is a sign of inferiority.[144] The myth of independence continues to the present, as does the presumed inferiority of those deemed or made dependent. It is a myth that again establishes a hierarchy of power, those who claim (however falsely) to be independent over and against those who depend upon them. It is not without reason that women, people of colour, and subjugated peoples have fought for their independence. To be dependent is to be stigmatised and rendered powerless, to be thought of as childlike, lazy, weak, and/or vulnerable (consider the shame that attaches to welfare dependency).[145] Independence is the ideal of responsible adulthood, but the underside of this ideal is the stigmatised and infantilised person with disability, a stigma that carries over to family carers and support workers, whose pay (nothing or a pittance) reflects the value that attends to their work.[146]

For good reason, disability activists have rejected paternalism and emphasised the right of people with disability to exercise autonomy, but there is danger that this emphasis accedes to the independence myth. People with disability, as with everyone, are dependent upon others and the wider society for some or other vital function or capability.

As a person with quadriplegia for example, I need help for basic activities throughout the day, like getting into and out of bed, showering, getting dressed, eating, deciding upon medication, and so on. I had to learn that dependency is not the end of my independence but, rather, its partner; that receiving the support on which I was dependent facilitated my independence. Humanity is a social species whose flourishing is achieved by our interdependence, even if we generally fail to admit (and celebrate) the fact. The experience of disability is a sign that every person needs support to maximise independence.[147]

Disability advocates generally understand independence in terms of autonomous choice, yet no one's choices are truly independent. People with intellectual disability maximise their autonomy by appropriately directed support, including education directed at their learning needs, text written in language that they can understand, and support workers that help to translate complex ideas. With appropriate support to help understand issues at hand and implement their desires and intentions, most people with intellectual disability can live in independent accommodation, enjoy deep (and sexual) relationships, work for a living, raise children, and make choices about their own future in much the same way as the wider society (as social role valorisation suggests—see subsequent discussion). Again, independence does not belie dependence but is achieved through it, and this insight has vital implications. For example, one of the aims of the NDIS is to provide early support to people to enable them to learn skills to maximise their future independence, with the hope that early investment will reduce long-term costs. But for many people, independence is achieved, not by reducing their support over time, but by improving its quality. There is a fine but important distinction between paternalistic care and active support.[148] The former diminishes a person's power increases their vulnerability, the latter empowers dignity and choice and makes a person stronger.

Vulnerability is itself a concept in need of reframing. Like dependency, it is normally used to define marginal and 'weak' populations, and is thus also a stigmatising term.[149] Vulnerable populations are perceived as needing protection, as victims, and thus paternalism generally guides society's response. Vulnerable groups, such as people with disability, have their agency withheld, behaviour monitored, and are subject to segregation—all for their own apparent protection.[150] Rather than see 'the vulnerable' as

other, however, vulnerability should be understood as a product of our embodiment, which carries the ever present possibility of harm, disability, violence, and death.[151] Vulnerability is thus universal, central to the human condition. Affirming its universality can free vulnerability from its negative and othering associations and provide a basis for the development of policy and institutions that lessen our vulnerability by empowerment rather than control. In the context of disability, this entails ensuring that people have access to the material assets and social supports they need to maximise their strength and resilience in the face of the risks related to their particular embodiment.[152]

Social role valorisation

The notion of active support comes from *social role valorisation*, which is another strand of disability theorising and advocacy running parallel with the social model (and sometimes in opposition to it). It emerged from academics and service providers working with people with intellectual disability. They argue that the social model is too often championed by people with physical impairments, who originally defined disability by reference to physical capacity, emphasised independence and autonomy, and presumed to speak for all people with disability. Too often, social model advocacy was yet another instance of power imbalance in which marginalised the needs, concerns, and voices of people with intellectual disability.[153] The suitability of the social model for intellectual disability was also questioned, given that learning difficulties are often educational rather than medical constructs, and thus the medical/social dichotomy is largely irrelevant (although the history of eugenics involves medico's shaping social policy with respect to 'problem populations', including attempts to eliminate people with intellectual disability[154]).

Social role valorisation was originally labelled normalisation theory.[155] Confronting the oppression and marginalisation of people with intellectual disability who, as a social group, have occupied devalued roles in society, social role valorisation asserts that the needs of people with intellectual disability are 'basically the same as those of ordinary people,' and they should therefore be supported to live as close to normal lives as possible.[156] As a devalued social group, one still subject to eugenic logic, people with intellectual disability have been rendered powerless and subjected to the systemic violence of segregation, where the abuses they suffer are out of view and unimportant.

Social role valorisation (or normalisation) is achieved by enhancing the social situation and image of people with intellectual disability, and developing and supporting their personal competencies. It has made an important contribution to the deinstitutionalisation agenda in accommodation settings and the push for social inclusion and participation in mainstream social networks, including in schools, the workplace, and other community settings (supported by disability advocates with physical and intellectual disability and some support workers).[157]

Given its concession to the 'normal', critics argue that social role valorisation perpetuates internalised ableism, sustains the power imbalance between professionals and people with intellectual disability, and ignores the social construction of intellectual disability.[158] Its defenders assert that reference to the normal is not an affirmation of an ableist ideal but, rather, a critique of the devaluation of people with intellectual disability—that the intent is to normalise disability and insist on a common humanity. They also argue that the critique of normalisation (as it is still labelled by critics) is largely ideological, that the real concern is that it is at odds with the types of empowerment strategies used by other devalued groups who have instead elevated their differences.[159]

It is difficult, however, for social role valorisation to escape the critique that, despite its attempt to distinguish the normal from normalisation, its valorising of social roles is inextricably ableist.[160] In the pursuit of valued social roles, it inevitably reproduces typical assumptions about those roles, ignoring that the construction of social roles can be stereotyped and oppressive—sexist, racist, and homophobic.[161] Cultural and ableist theories, in contrast, looks to challenge and reconstruct social role expectations to accommodate difference.

Both the social model and social role valorisation have changed and developed over time, and there is increasing recognition that the former should embrace some insights of the latter. People with intellectual disability have asserted that people with physical disability need to 'respect us, listen to us, learn from us, and not lecture us about what we should think.'[162] These assertions are essentially what the social model itself is all about. Intelligence is at least in part socially constructed (diagnosed by IQ tests, which are inherently cultural and ideological),[163] and people with intellectual disability have been subject of paternalism, ableism, and marginalisation, and live within social systems

designed without taking their learning needs into account and which present substantive barriers to their health and well-being.[164] Even so, for the social model to make sense for people with intellectual disability, it will need to pay closer attention to the role of cognitive impairment on their experience of the social world.

Care and people with high level support needs

Even though we are all interdependent, relationships between carer and cared for tend to be hierarchical, and even carers with the best intentions are in danger of diminishing the power of the person reliant on support. People with disability have noted that 'care' can become a form of domination, and have sought to shift the balance of power by changing the terminology from 'carer' to 'client', 'consumer' or 'support worker,' with mixed success.[165]

Carers of people with high support needs, however, argue that disability theorist's and advocate's emphasis on independence and autonomous choice excludes the needs of people whose impairment makes such autonomy near impossible.[166] While the independence of some people may be served by changing the dynamics of support, for others relationships characterised by closeness, empathy, mutual liking, trust, and rapport enable a person to communicate their desires and feel comfortable to engage with others in meaningful activities.[167] In critiquing the elevation of independence that tends to prioritise men over women, some feminists have observed that dependent relationships such as between a mother and her disabled child need not imply hierarchy, but denote an essentially equality derived from the vulnerability and dependency that are a central feature of the human condition.[168] To lose sight of the value of care diminishes the person in need of care and the carer. Care ethics is not just a personal issue between a carer and the person being cared for, but has political significance, and demands a re-evaluation in how we think about and value care (both voluntary and paid) and its relation to other types of work.[169]

Adults with disability generally appreciate the care that they have received, but have responded to critique of the priority they give to autonomy by noting that well-meaning parents do not always act in the liberating interests of their child (and nor do well-meaning support workers).[170] Parents of children with high-level intellectual disability are

as likely as anyone to come to the task of parenting with ableist attitudes and unless they are able to learn about disability from the disabled community they may unwittingly perpetuate ableist biases and attendant hierarchies of power and violence. This bias is obvious in growth attenuation therapy, but more subtle in the preference of some parents and principals for segregated special education that is systemically ableist and exclusionary, and ignores the body of evidence that shows that properly constituted inclusive education has better long-term outcomes.[171] For the purposes of this paper, it is enough to note the ambiguity of independence. The goal of maximising the autonomous choice of people with disability is often facilitated by care and support, and the vulnerability that arises from dependency means that there are risks whichever way one turns.

Justice and human rights

Capabilities

In addition to specific models and theories of disability, scholars have applied broader theories of justice to the context of disability. One prominent example is the capabilities approach. Based on a rejection of the prevailing assumption that the possession of goods or resources is an inadequate approach to justice, the capabilities approach focuses on what people are capable of becoming or doing, the various 'functionings' they can achieve. It identifies a list (open to revision) of central human capabilities that are implicit to a life of worth and dignity, that make it possible for a person to flourish in their own way, and that provide a minimum basis for human rights.[172] These capabilities include being able to,

i) enjoy a life worth living without dying prematurely,
ii) have good health, including access to food, shelter, and other vital needs,
iii) experience bodily integrity, such as security against violence, and the opportunity for sexual satisfaction and choice in matters of reproduction,
iv) use the senses to imagine, think, and reason, have access to education to develop these capacities, and freedom of speech and religion,
v) experience emotions such as love and have attachments to people and things,
vi) exercise practical reason and autonomy in planning one's own life,

vii)   affiliate with others, engage socially, and be treated with dignity and worth,

viii)   live with concern for and interact with the natural world,

ix)   play, laugh, and enjoy life, and

x)   exercise control over one's environment, including making political choices and having basic property rights.[173]

While not explicitly targeting sociocultural hierarchies and power structures, the capabilities are an affirmation of a person's effective powers, and their emphasis on universal dignity, capacity, equality, education, autonomy, control, and choice is aligned with the empowerment intended by social and cultural theorists. It also concretely addresses sources of bondage and structural violence, declaring as unjust the prevailing assumption that people with disability would be better off dead, and insisting on the integrity of a person's body against violence (including non-consensual medical intervention). It elevates personal agency across a broad sphere of human life, and provides a minimal set of normative categories to which social and cultural theories can direct their attention and help to inform policy. All ten capabilities are declared universally relevant, the right of every person, and the list is not ranked in order of priority, since to do so would undermine their universality.

There is concern that the capabilities approach diminishes the personhood of people whose impairment prevents them from exercising all of the capabilities, and that it thus involves a ranking of persons who can and cannot exercise characteristics.[174] Yet, while impairment may prevent some individuals from achieving all capabilities on their own, the capabilities approach asserts that necessary and appropriate supports should be directed at their attainment. While for much of human history, the presumption has been that people with disability are inherently incapable (and so less than human), the capabilities approach makes the full gamut of human experience a matter of justice. Critics note that no amount of social reorganisation or resource allocation will change the fact that some capabilities will be unachievable for people with very particular cognitive impairments, so that the capabilities approach disrespects their human dignity.[175] Yet in cases of people with high-level needs, it may be that capabilities such as political choice and property rights are enabled by interdependency or collectively, as First Nations peoples have shown, in conjunction with family and the community. Affirming a universal list of

capabilities challenges the tendency to presume too quickly what a person with disability can and cannot do and be, and strives for maximum capability.[176]

Convention on the Rights of Persons with Disabilities (CRPD)

There is an obvious parallel between the capabilities approach to justice and formal human rights mechanisms, although since the latter are politically negotiated, it has been argued that the capabilities can provide an ethical foundation for rights policies such as the CDRP.[177] Others assert that the *CRPD* itself presents us with a human rights model of disability, one that focuses on human dignity and understands people with disabilities, not as objects of charity and medical treatment, but as subjects of rights and active members of society.[178] While the CRPD represents a paradigm shift in global disability policy, it is not itself a theory or model of disability but, rather, an attempt to apply general human rights policy to the emergent perspectives on disability that have been laid out earlier.[179] It is beyond the scope of this paper to describe and analyse the CRPD in full, but its primary achievement is to obligate State Parties to promote a fundamental change in societal attitudes and structures and to foster respect for the dignity of persons with disability and their right to follow effective participation and inclusion in society. In the preamble, the *CRPD* says that:

> disability an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.[180]

This definition incorporates the insight of the social model, without dichotomising the medical and the social. It also draws on cultural theory, pointing to the importance of embodiment and cultural values (attitudes).

After laying general principles and provisions, the *CRPD* seeks to ensure that people with disability have full civil, political, economic, social, and cultural rights. In doing so, it often clarifies and broadens traditional rights in the light of the specific experience of disability, such as its extension of the right to freedom from torture to include freedom from all forms of exploitation, violence, and abuse (Article 16).[181] Similarly, it understands the right to liberty as entailing the right to choose where and with whom to live as well as

proactive effort to ensure that people with disability are provided with the support, mobility aids, and technologies that they need to participate fully in society (articles 10 and 20). Further, it clarifies that the right to equality before the law requires States to recognise that people with disability have an equal right to legal capacity and States must ensure access to supports people with disability may need to exercise legal capacity (Article 12). In making these innovations, the CRPD has the potential to inform the rights of people with and without disability.

The CRPD does not always live up to the ideals of disability advocacy and theory. A far too brief Article 17, for example, provides persons with disability the right for respect of their physical and mental integrity, but does not explicitly address the problem of compulsory treatments (although treaty monitoring bodies have interpreted Article 17, read in light of other articles, as prohibiting compulsory or forced treatments).[182] The distinction between disability theory and human rights policy enables the critical distance that is important to the development of disability related policy.

Conclusion

Disability is a construct with evolving meanings that have developed over time. Historically, its meanings have been hoisted on people with disability by others with professional, political, and cultural power, who have used those meanings benevolently and violently, to categorise, control, stigmatise, heal, hide, and sometimes eliminate people. The models and theories of disability that have developed with the disability rights movement are a product of disabled people—and here I include myself—taking control of our own meanings.[183] As with any emerging field of knowledge, there are distinct perspectives and disagreements but, on the whole, these differences are complementary and there is growing consensus. Far from being abnormal, disability is an expression of human diversity, vulnerability, and strength. In all its varieties, disability theory is a criticism of ableism and paternalism, a deconstruction of hierarchies of power, and an effort to transform attitudes, values, and systems. It intends to empower our personal and collective thinking to help us resist violence, make choices about our own future, and flourish in our own way.

The concrete implications of disability theories and models for resisting the violence, abuse, neglect and exploitation that is too often experienced by people with disability include the following:

- Unmasking the charity model of disability challenges attitudes of pity that create dependency and render people with disability powerless and vulnerable to systemic violence and neglect. It encourages recognition of the expertise and contribution people with disability can make to their own well-being and that of others, and looks to facilitate disability leadership and coproduction in the delivery of services.

- Critiquing the medical model of disability challenges the assumption that disability is a tragedy that needs to be cured, eliminated, or segregated. Far from opposing medicine, rejecting the medical model ensures that people with disability have the same right to quality healthcare as those without disability. It confronts the tendency to reduce people to their diagnosis or classification, and highlights the dangers of paternalism.

- Advocating for the social model of disability switches the focus of disability policy from individual impairments to the transformation of social systems that exclude, disempower, and discriminate. It seeks to make the social world accessible by transforming the built environment and providing appropriate means of communication and support to ensure people have access to knowledge and can make autonomous choices. It understands that health and well-being are socially determined, and so looks to transform material conditions by creating accessible accommodation, education, employment and providing a sufficient income and social services for a person to live well.

- Utilising cultural and critical theories helps to unmask disabling ideology and the production and practices of ableism, and show how abled privilege can be propagated by religions, literature, media, music, political debate, policy and so on. They also highlight sources of empowering attitudes and values. Cultural theories complement the social model by affirming embodiment, the bodily experience of the social world.

- Feminist disability theory highlights the intersections between sexism and disability and the importance of identifying and criminalising violence in all settings, domestic and institutional.

- Emerging disability voices from the global south elevate the ongoing consequences of historical, colonising violence, and emphasise the value in addressing the systemic causes of violence, abuse, neglect and exploitation. Awareness of First Nations peoples' understandings of people with impairments not only encourages us to respect their culture and ways of living, but challenges us to learn from their inclusive traditions and practices.

- Understanding theoretical debates about independence, dependence, and interdependence helps us to balance systems that elevate care and those that empower autonomy (the dignity of risk). They are a reminder of the important role played by parents and support workers in the amelioration of risk and care of some people with disability, as well as the danger of paternalism and the goal maximising independence. Support and care are not the opposite of independence, but facilitate it.

- Drawing on social role valorisation reminds us that people with intellectual disability can be supported to live with much the same opportunities available to people without disability. It resists the danger of violent institutional control, and encourages social inclusion.

- Using the capabilities approach to justice provides an insight into the diverse capabilities that all people with disability have the right to experience. Similarly, drawing on the CRPD helps us to understand the diverse rights and freedoms of people with disability, and obligates states to promote, protect, and facilitate those rights.

- Finally, embodied disability and intersectional complexity highlight the multifaceted nature of the causality of violence, abuse, neglect and exploitation against people with disability. It stands as an important reminder that solutions to disablement will not be straightforward.[184] Admitting complexity is not to concede that violence and disadvantage are impossible to solve, but to embrace a multi-dimensional response (individual, social, cultural), to listen to the expertise of people with disability and coproduce services with us, to appreciate the importance of direct

and indirect solutions (such as the social determinants of health), and to take a short and long-term view (understanding the cyclical and intergenerational challenge of disadvantage). Recognising and affirming the diversity and complexity of disability should inspire creativity, encourage experimentation, and motivate us to work through failure for the sake of creating a world that enables people with disability to flourish.[185]

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[183] I use the collective 'we' in this conclusion, and identity first language, to locate myself as a proud beneficiary of the work and theorising of the disability community. I hope in my own small way to help carry it forward.

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[185] The ideas in this paragraph emerge from presentations by Leanne Dowse and Lorna Hallahan to the staff of the disability Royal commission.

Royal Commission

into Violence, Abuse, Neglect and
Exploitation of People with Disability