

THE STATE OF MENTAL HEALTH IN UGANDA:

A Case Study of
Inclusion of
People Living
with Down
Syndrome
in Uganda.



MULONGO DIASPORA
FOUNDATION
SERVING COMMUNITIES



Atukunzire Vanita - 4 years
lives with a single mother in Kitintale suburb
of Kampala, Uganda.



First published in 2023

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ABSTRACT

The current study sought to discuss the state of mental health in Uganda and looked at a case study of inclusion of people with Down syndrome in Uganda. While adopting a case study design, using quantitative method, the study established that though Down syndrome is a disability, people with Down syndrome and their caregivers are vulnerable to mental health issues if exposed to exclusive environments.

The study further found that though Uganda has legal framework which provide for inclusion of people with Down syndrome, people with Down syndrome are still facing exclusion in education, employment, health care and communities due to poor implementation of inclusion laws and polices coupled with lack of data on prevalence of Down syndrome in Uganda in addition lack of awareness, lack of specialized medical treatment and education for people with down syndrome. Pursuant that the above finding, the study concluded that people with Down syndrome Uganda and their care givers are vulnerable to depression, anxiety and other mental health issues.

The study recommended conducting disability census, awareness creation, funding education and health services for people with Down syndrome, making regulations to guide the implementation the laws, putting into place health insurance, building of center for people with Down syndrome and offering vocational skills ,life skills and talent building to people with down syndrome as the

best way to promote inclusion of people with Down syndrome which will in return promote mental health of people with Down syndrome and their care givers in Uganda.

GLOSSARY OF TERMS

Disability

Disability is defined as a substantial functional limitation of a person's daily life activities caused by physical, mental or sensory impairment and environment barriers, resulting in limited participation in society on equal basis with others¹and it include impairments like mental disability which comprise of psychiatric disability and learning disability.²

Mental Disability

Mental Disability refers to impairments or conditions that have a long-term effect on a person's mental well-being³which include; psychiatric disability and learning disability.⁴

Psychiatric disability

Psychiatric disability refers to a term used when mental illness significantly interferes with the performance of major life activities, such as learning, working, and communicating, among others.⁵

¹ Person with Disability Act 2020 (PWDA) s 1(1).

² Ibid schedule 3.

³Collins English Dictionary, ` Definition of 'mental disability ' HarperCollins Publishers < www.collinsdictionary.com/dictionary/english/mental-disability> accessed 3 February 2023.

⁴ PWDA schedule 3.

⁵ The Parliament Of Uganda, `Report of the Sectorial Committee on Health on the Mental Health Bill 2014 (2018) Parliament 6.

Learning disability

Learning disability is a neurological condition which affects the brain's ability to send, receive, and process information which results to difficulties in reading, writing, speaking, listening, understanding mathematical concepts, and with general comprehension including dyslexia, dyspraxia, dyscalculia and dysgraphia.⁶

Intellectual disability

Intellectual disability is a disorder defined by the presence of incomplete or arrested mental development, principally characterized by the deterioration of concrete functions at each stage of development and that contribute to the overall level of intelligence such as, cognitive, language, motor and socialization functions; in this anomaly, adaptation to the environment is always affected.⁷

Mental health

Mental health is defined as a state of well-being whereby individuals recognize that their abilities, are able to cope with the normal stresses of life, work productively and fruitfully, and make a contribution to their communities.⁸

Mental Illness

Mental illness refers to a diagnosis of mental health condition in-terms of accepted diagnostic criteria made by a mental health practitioner or medical practitioner authorized to make such

⁶ Whites Wan Foundation , `Neurodevelopmental Disorders Learning Disability' (23 January 2015) <www.whiteswanfoundation.org/disorders/neurodevelopmental-disorders/learning-disability > accessed 6 March 2023.

⁷ Gregorio Katz and Eduardo Lazcano-Ponce, `Intellectual Disability: Definition, Etiological Factors, Classification, Diagnosis, Treatment and Prognosis' (2008) 50(2) SPM 133.

⁸ World Health Organization ` Investing in Mental Health' (2003) 7 <<https://apps.who.int/iris/bitstream/handle/10665/42823/9241562579.pdf> > accessed 3 February 2023.



Down syndrome refers to hereditary disorder resulting in humans from trisomy of chromosomes that leads to multiple abnormalities such as recurrent respiratory infections and a heart defect.¹³

ACRONYMS

CRDP	Convention on the Rights of Persons with Disabilities
DS	Down syndrome
NGO	Non-governmental Organization
NPD	National Planning Authority
UBOS	Uganda Bureau of Statistics
UN	United Nations

¹³ Mohammad Kazemi, Mansoor Salehi and Majid Kheirollahi ` Down syndrome: Current Status, Challenges and Future Perspectives '(2016) 5(3) IJMCM 125.

CHAPTER ONE

1.1 General Introduction

Mental health is defined as a state of well-being whereby individuals recognize that their abilities, are able to cope with the normal stresses of life, work productively and fruitfully, and make a contribution to their communities.¹⁴

On the other hand, mental disorders are diseases that affect cognition, emotion and behavioral control and substantially interfere both with the ability of children to learn and the ability of adults to function in their families, at work, and in the broader society.¹⁵

The major types of mental disorders include: Mood disorders like major depressive disorder, dysthymic disorder and bipolar disorder¹⁶; Anxiety disorders which include panic disorder, obsessive-compulsive disorder, post-traumatic stress disorder, generalized anxiety disorder and phobias social phobia, agoraphobia and specific phobia¹⁷; Eating disorders which also include anorexia nervosa, bulimia nervosa and binge-eating disorder¹⁸and personality disorders which include; avoidant personality disorder antisocial personality disorder and borderline personality disorder.¹⁹

In Uganda, about 14 million people out of the 43.7 million of Uganda's population have mental illness.²⁰The approximate prevalence of about 32.0% was higher than in previous national estimates of 24.2% due to the pervasive social stigma and taboos associated with accessing mental health services.²¹ Further, the primary care system in Uganda is poorly resourced, inadequately

¹⁴World Health Organization (n 8).

¹⁵ World Health Organization (n 10).

¹⁶ National Institute of Mental Health, 'Common Mental Health Disorder' 1
<<https://frdat.niagara.edu/assets/Disability-Handouts/Common-MH-Disorders.pdf>> accessed on 3rd February 2023.

¹⁷ Ibid.

¹⁸Ibid 2.

¹⁹ Ibid 3.

²⁰ Mark Mohan Kaggwa, Sheila Harms, Mohammed A Mamun 'Mental health care in Uganda', (2022) 9 Lancet 766
<<https://www.thelancet.com/action/showPdf?pii=S2215-0366%2822%2900305-4>> accessed 3 February 2023.

²¹Ibid.

funded, and ill-equipped to address mental health concerns and nationwide, there are only 53 psychiatrists approximately one psychiatrist per 1 million population.²²The major mental health problems in Uganda include: mental, neurological and substance use disorders.²³However, depression, anxiety disorders, and elevated stress levels are the most prevalent.²⁴

Down syndrome refers to hereditary disorder resulting in humans from trisomy of chromosomes that leads to multiple abnormalities such as recurrent respiratory infections and a heart defect.²⁵ There are three types of Down syndrome which include; trisomy, mosaic and translocation with the most common one being trisomy.²⁶

Children with Down syndrome have well defined physical characteristics as such, they can be identified at birth or shortly thereafter and the diagnosis is confirmed with chromosomal analysis.²⁷ They also have delayed physical growth and mild to severe intellectual disability and their typical mental ability is below 10 years.²⁸

It is important to note that maintaining a good state of mental health of people with Down syndrome is only possible where they are supported by a nurturing and responsive environment. However, people with Down syndrome and their families often face hardship in accessing health services, education, transport and other services as well as undergo stigma, bullying and

²²Ibid.

²³James Mugisha, Charlotte Hanlon, Brithe L Knizek, Joshua Ssebunnya, Davy Vancampfort, Eugune Kinyanda and Fred Kigozi. 'The Experience of Mental Health Service Users in Health System Strengthening: Lessons from Uganda' (2019) 13 IJMH 60 < <https://doi.org/10.1186/s13033-019-0316-5> > accessed 3 February 2023.

²⁴ Ibid.

²⁵ Kazemi (n 13).

²⁶ WebMD Editorial Contributors, 'Down Syndrome' (2022) < www.webmd.com/children/understanding-down-syndrome-basics > accessed 3 February 2023.

²⁷ The Public Health Agency of Canada's, 'Down Syndrome Surveillance In Canada, 2005-2013' (2013) < www.canada.ca/content/dam/phac-aspc/documents/services/publications/healthy-living/down-syndrome-surveillance-2005-2013/pub1-eng.pdf > 3 February 2023.

²⁸Venera Krasniqi, Katerina Zdravkova and Fisnik Dalip, 'Impact of Assistive Technologies to Inclusive Education and Independent Life of Down Syndrome Persons: A Systematic Literature Review and Research Agenda Sustainability' (2022) 14(8) MDPI 2 < www.diva-portal.org/smash/get/diva2:1651717/FULLTEXT01.pdf > accessed 7 February 2023.

discrimination on top of the everyday demands of coping with the impairment.²⁹ This has made them vulnerable to diagnosable mental disorders³⁰ like mood disorders (including depression); anxiety disorders (including obsessive-compulsive disorder); schizophrenia; psychosis (including hallucinations); pseudobulbar affect; personality disorder; dementia (including Alzheimer's disease);³¹ mental disorder due to physiologic causes; ³² conduct disorder; tic disorder and impulse control disorder³³ and oppositional behaviors.³⁴ As such, this study sought to find out about inclusion of people with Down syndrome in Uganda to come up with a conclusion on the state of mental health in Uganda in relation to people with Down syndrome in Uganda and the care givers.

1.2 Background of the Study

In Uganda, it estimated 12% of the population have a disability³⁵ with over 5,000 people estimated to be living with Down syndrome.³⁶ Uganda is a signatory to the UN Convention on the Rights of Persons with Disabilities³⁷ and has made a commitment to promote equal rights and opportunities for persons with disabilities which is reflected in the Constitution of the Republic of Uganda

²⁹ Judith McKenzie, Lieketseng Ned, Brian Watermeyer and Shakila Dada 'Disability and Mental Health: Addressing Discrimination and Enhancing Participation' (2022) South African Child Gauge 137.

³⁰ The Public Health Agency of Canada's (n 27).

³¹ Anne Rivelli, Veronica Fitzpatrick, Sagar Chaudhari, Laura Chicoine, Gengjie Jia, Andrey Rzhetsky, Brian Chicoine, 'Prevalence of Mental Health Conditions Among 6078 Individuals With Down Syndrome in the United States' (2022) 9(1) Patient Cent Res Rev 58-63.

³² Vee Prasher and Neha Bansal, 'Psychiatric Mobility in Adults with Dawn Syndrome,' (2006) University of Hertfordshire < www.intellectualdisability.info/mental-health/articles/psychiatric-morbidity-in-adults-with-downs-syndrome > accessed 4 February 2023.

³³ Rivelli (n 31).

³⁴ Dennis McGuire and Brian Chicoine, *Mental Wellness in adults with Down syndrome: A Guide to Emotional and Behavioral Strengths and Challenges* (1st Edn Woodbine House, 2006) <<https://ndss.org/resources/mental-health-down-syndrome>> accessed 4 February 2023.

³⁵ Uganda Bureau of Statistics, 'National Housing and Population Census 2014' (2016) <<https://uganda.unfpa.org/en/publications/national-population-and-housing-census-2014-0>> accessed 3 February 2023.

³⁶ Bryn Gelaro, Jerry Amany, Michelle Sie Whitten, James M. Van Leeuwen, Megan Lindstrom, Thomas Karrel, and Jonathan Pinckney, 'Down Syndrome In Uganda: Identifying Barriers and Making Recommendations to Increase Access' (2019) 2(4) IJSSMR 86.

³⁷ Ministry of Gender, Labour and Social Development, 'Situational Analysis of Persons with Disabilities in Uganda,' (2020) 114.

(1995),³⁸ the Persons with Disability Act 2020³⁹ and the Mental Health Act 2018⁴⁰ which apply to people with Down syndrome as well.

Although a lot been done in terms of establishing policy and legal frameworks for mainstreaming equality and inclusion, less has been done in bid to operationalize those frameworks as result, people with Down syndrome in Uganda are still facing discrimination and neglect ⁴¹without medical care and education.⁴² It was upon this background that the Organization felt the need to conduct a study to establish the state of mental health in Uganda with specific focus on inclusion of people with Down syndrome.

1.3 Statement of Problem

Adequate implementation of laws promotes inclusion of people with Down syndrome which promotes mental health. Despite amending the Mental Health Act, 2018 and enacting the Persons with Disabilities Act 2020 and putting in place several disability inclusion polices, people with Down syndrome are still being discriminated, and neglected⁴³without health care, employment and education.⁴⁴Currently, it is estimated that there are 5,000 people with Down syndrome in Uganda.⁴⁵The magnitude of the danger posed by poor implementation of disability inclusion laws and polices cannot be ignored since the mental health of over 5,0000 Ugandans with Down syndrome and their care givers are likely to be negatively affected if not addressed. It against this back ground that the organization felt the need to conduct a study to find out the state of mental health in Uganda with a specific focus on the implementation of the laws and policies on disability inclusion to come up with recommendations on how best inclusion can be implemented in Uganda to promote mental health of people with Down syndrome and their care givers.

³⁸ Ibid 7.

³⁹ PWDA 2020 s1 (1) and schedule 3 Item 5.

⁴⁰ MHA 2018.

⁴¹ Kate Sullivan, 'Down syndrome in Uganda' (2015) Global Livingston Institute 2-3.

⁴²Gelaro (n36) 87.

⁴³ Sullivan (n 41) 2.

⁴⁴Gelaro (n 36)87.

⁴⁵ Ibid 86.

1.4 Research Question

1. Which laws provide for inclusion of people with Down syndrome in Uganda?
2. What barriers have affected promotion of inclusion of people with Down syndrome in Uganda?
3. What challenges are care givers of people with Down syndrome facing in Uganda?
4. What practices have been adopted by other jurisdictions in promoting inclusion of people with Down syndrome?
5. What mechanisms can be used to promote inclusion of people with Down syndrome in Uganda?

1.5 Objectives of the Study

1.5.1 General Objectives

The study sought to analyze the state of mental health in Uganda with a specific focus on inclusion of people with Down syndrome in Uganda.

1.5.2 Specific Objectives of the Study

1. To identify and examine laws which provide for inclusion of people with Down syndrome in Uganda.
2. To discuss barriers to inclusion of people with Down syndrome in Uganda.
3. To discuss the challenges which care givers of people with Down syndrome are facing in Uganda.
4. To analyze practices which were adopted by other jurisdictions in promoting inclusion of people with Down syndrome.
5. To suggest possible ways in which inclusion of people with Down syndrome can be promoted in Uganda.

1.6 Significance of the Study

To the academic world, this study will constitute a body of knowledge highlighting the state of mental health in Uganda a case of study of inclusion of people with Down syndrome.

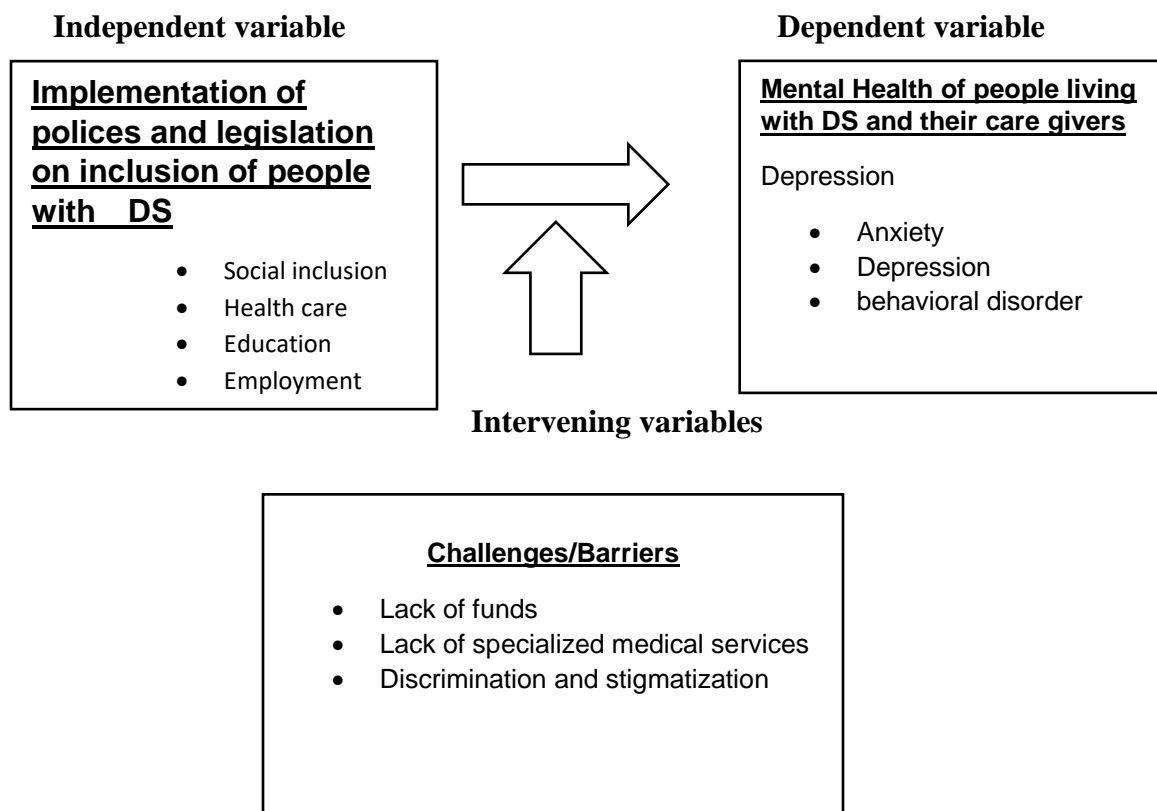
This study will also provide a guide to the legislature and policy makers in making Down syndrome inclusive polices as well as provide information for other stakeholders like advocates, lawyers,

researchers and that will use the study as a guide in promoting inclusion of people with Down syndrome in Uganda.

1.7 Conceptual Framework

The conceptual framework was developed from the relationship between, implementation of Down syndrome inclusive laws and policies as the independent variable, barriers to the promotion of inclusion and resilience of people with Down syndrome as the intervening variables and mental health of people with Down syndrome as dependent variable. All those variables were relevant in discussing the state of mental in Uganda while looking at the inclusion of people with Down syndrome as the case study.

Figure 1



1.8 Research Methodology

This study was conducted using qualitative method and a descriptive design. While adopting qualitative research,⁴⁶ data was collected from both primary and secondary data. The primary data was collected using structured interview guides which were administered to the purposively sampled 15 interviewees, ie 2 from homes, 2 from NGO's, 2 from Government institutions and caregivers of people living with Down syndrome in Uganda.

Upon completion of data collection, major themes were identified and data was presented thematically in line with the research questions. The findings and data collected from secondary and primary sources were used to draw conclusions and give recommendations. Data was presented using descriptive analysis.

1.9 Scope of the Study

1.9.1 Content Scope

The content scope of the study was the state of mental health in Uganda a case study inclusion of people with of Down syndrome.

1.9.2 Geographical Scope

The study was conducted in two districts in Uganda that is to say, Kampala and Wakiso. These districts were identified because they were accessible within the limited time of the research and they provided diverse perceptions and experiences in regards to inclusion of people with Down syndrome which enabled accuracy in the data presented.

1.9.3 Time Scope.

The study was carried out from 3rd February 2023 to 23th March 2023.

1.10 Limitations of the Study.

The organization encountered time constraints since the time period within which the study was conducted was very limited compared to wide scope of the study. This limitation was mitigated

⁴⁶ Olive M. Mugenda and Abel G. Mugenda, *Research Methods: Quantitative and Qualitative Approaches*. (Thomson Publishers 2003) 31.

by drawing up a timetable which was strictly followed to overcome the time barriers and focusing on the required scope. Further, the data on implementation of inclusive legislations and policies in other jurisdictions were limited as such, the study was restricted to the available information.

1.11 Literature Review

This part presents a discussion of the scholarly materials that address inclusion of people with Down syndrome as means of promoting mental health.

1.11.1 The relationship between Down syndrome and Mental Health

Anne Rivelli et al note that the connection that exist between Down Syndrome and Mental health is that people with Down syndrome are vulnerable to mental health issues⁴⁷like mood disorders (including depression); anxiety disorders (including obsessive-compulsive disorder); schizophrenia; psychosis (including hallucinations); pseudobulbar affect; personality disorder; dementia (including Alzheimer’s disease);⁴⁸mental disorder due to physiologic causes;⁴⁹ conduct disorder; tic disorder; and impulse control disorder⁵⁰ and oppositional behaviors.⁵¹

On the other hand, Canadian Down syndrome Society and Down Syndrome Resource Association note that both people with Down syndrome and their care givers have a heightened risk of mental health issues including anxiety, depression, elevated stress level and more.⁵² According to Ashimwe the mental health issues among people with disabilities are associated with emotional climate at home and at school where most persons with disabilities are predominantly victims of attitudinal biases.⁵³

⁴⁷ The Public Health Agency of Canada’s (n 27).

⁴⁸ Rivelli (n 30).

⁴⁹ Vee Prasher (n 31).

⁵⁰ Rivelli (n 30).

⁵¹McGuire (n 34).

⁵² Canadian Down syndrome Society and Down Syndrome Resource Association, ‘Mental Health for Health for Parents & Parents & Caregivers: Canada’s Down Syndrome Magazine’ (2022) 9 Canada Down Syndrome Society and Down Syndrome Resource Association 2 <<https://cdss.ca/wp-content/uploads/2021/12/321-magazine-WINTER-2022.pdf>>accessed 4 February 2023.

⁵³Ange Ashimwe, ‘Disability and resilience: Why the storyteller matters’ (University World News, 17 June 2021) <www.universityworldnews.com/post.php?story=20210616085819533>accessed 5 February 2023.

Down syndrome Australia notes that people with Down syndrome experience mental illness than people without disability due to social and health barriers rather than the disability itself. It further notes that those social barriers include; poor community inclusion, bullying, low expectations, limited access to meaningful work and social activities while health barrier include; lack of appropriate doctors or therapists ,doctors attributing symptoms to Down syndrome rather than mental health, difficulty in understanding effective ways of maintaining good mental health or understanding treatment for mental illness, difficulty in communicating and expressing feelings which makes it hard for them to talk about issues affecting mental health.⁵⁴

While a study conducted by Dias et al on the impact of caregiving of children with Down syndrome on parenting quality of life stress, mental and oral health found that caregiving of children with DS has an impact on parenting oral health and stress.⁵⁵

The findings of those authors provided the basis of this research which sought to use inclusion of people with Down syndrome to draw conclusions on the state of mental health of people with Down syndrome in Uganda and their care givers.

1.11.2 Relevance of Inclusion to the mental health of people with Down syndrome.

Center for Diseases Control and prevention notes that disability inclusion allows people with disabilities to take advantage of the benefits of the same health promotion and prevention activities experienced by people who do not have disabilities.⁵⁶

While inclusion does away with exclusion barriers which causes mental health problems among people with Down syndrome and their care takers, Scheffers et al notes that resilience helps individuals to respond successfully and creatively to their disabilities and promotes the notion that individuals do not need to be defined by environmental problems, and there is no reason that these

⁵⁴ Down syndrome Australia, ` Down syndrome and Mental Health (2020) 3 <www.downsyndrome.org.au/act/wp-content/uploads/2020/02/DSAMentalhealthresourceweb.pdf >accessed 4 February 2023.

⁵⁵Caroline Dias , Carolina Schwertner , Débora Grando , Augusto Bacelo Bidinotto , Juliana Balbinot Hilgert , Jaqueline Bohrer Schuch , Lucas Araújo de Azeredo , Moisés Evandro Bauer , Lina Naomi Hashizume ` Caregiving of children with Down syndrome: impact on quality of life, stress, mental and oral health' (2022) 42(4) Pubmed 398-403 <<https://pubmed.ncbi.nlm.nih.gov/35014048/>> accessed 7 February 2023.

⁵⁶ Center for Diseases Control and Prevention, ` Disability Inclusion'<www.cdc.gov/ncbddd/disabilityandhealth/disability-inclusion.html> accessed 7 February 2023.

individuals cannot live healthy and successful lives resilience reinforces an underlying message that individuals do not need to be rescued and are not victims to their environments.⁵⁷

Much as the above discussion separates inclusion from resilience. It should be emphasized that inclusion empowers people in the process of recovery thereby, contributing to sustainable recovery and resilience building⁵⁸as such, resilience comes as a result of inclusion.

1.11.3 Laws that provide for inclusion of people with Down syndrome in Uganda.

Ministry of Gender, Labour and Social Development notes that in bid promote inclusion of people with disability, Uganda has signed international legislations advocating for the rights of persons with disabilities, including the Convention on Vocational Rehabilitation and Employment of Disabled Persons (1983); the Convention on the Elimination of All Forms of Discrimination against Women; the Convention on the Rights of a Child; and the UNCRPD (2008), the Constitution (1995),the Equal Opportunities Commission Act (2006), as well as the Children's Statute 1996 (with its 2016 amendments) and the Persons with Disability Act (2020) .⁵⁹ the ministry however notes that there is a significant gap between what is written on paper and what is being done on the ground since there is limited funding for the implementation of programmes, lack awareness of policies, inconsistencies across policies, discriminatory language and terms are still being used in those laws and limited enforcement of the aforesaid laws.⁶⁰ This report provides a detail analysis of disability legislative and policy framework for promoting inclusion and resilience of people with disability in Uganda in general but it does not align its discussion to Down syndrome which this study sought to address.

Development Initiatives notes that the government of Uganda has made various plans which also seek to address the need to protect and enhance the rights and inclusion of persons with disabilities.

⁵⁷ Femke Scheffers Eveline van Vugt and Xavier Moonen, 'Resilience in the Face of Adversity in Adults with an Intellectual Disability: A literature (2020) 33 JARID 828 .

⁵⁸ Asako Okai, 'Inclusion Contributes to Empowerment, Resilience and Development'(Reliefweb 14 May 2019) < <https://reliefweb.int/report/world/inclusion-contributes-empowerment-resilience-and-development>> accessed 7 February 2023.

⁵⁹ Ministry of Gender, Labour and Social Development (n 37)113-119.

⁶⁰ Ibid.

⁶¹ According to it, those plans include; the National Planning Authority’s (NPA) Second National Development Plan 2015/16–2019/20 (NDPII) which commits to design, implement and follow up the integration of human rights and disability responsive policies and the MoGLSD’s Social Development Sector Plan 2015/16–2019/20 (SDSP) which commits to enhancing community-based rehabilitation for children with disabilities and to improving access to disability grants for persons with disabilities. ⁶² It however, notes there are gaps in policies and plans as the solutions they present are limited in their scope and ambition as the SDSP set a target of reaching just 600 children per year between 2015 and 2020 and MoGLSD lack funds to finance its policy to increase the number of claimants accessing disability grants. ⁶³

Development initiative further notes that effective implementation of the plans, policies and strategies related to persons with disabilities has been a challenge because the ministries, departments, and agencies which are responsible for designing and implementing Uganda’s disability-relevant policies and plans are under resourced due lack of funds. ⁶⁴ Much as this study analyses the effectiveness of the disability inclusion legislation and policies, this report focused on disability data landscape in Uganda as such, it did not focus on the inclusion of people with Down syndrome specifically which his study sought to address.

1.11.4 Barriers to inclusion of people with Down syndrome in Uganda

Sullivan notes that lack of awareness about Down syndrome is prevalent in Uganda and that throughout Uganda, parents, families, and communities alike continue to associate Down syndrome with witchcraft and curses and communities believe that a child born with Down syndrome is a result of maternal misdeeds, or that the child is connected with the evil world. That due to this misconception, husbands often divorce their wives, leaving the mother alone to raise their disabled child, the children are kept from the outside world for fear of the shame as such,

⁶¹ Development Initiatives, ‘Uganda’s Disability Data Landscape and the Economic Inclusion of Persons with Disabilities’ (2020) 8 < <https://devinit.org/resources/uganda-disability-data-landscape-economic-inclusion-persons-with-disabilities/introduction/> > accessed 7 February 2023.

⁶² Ibid.

⁶³ Ibid.

⁶⁴ Ibid.

children with Down syndrome are stigmatized, discriminated, and neglected by the society.⁶⁵ She recommend that efforts on building awareness and appreciation of Down syndrome should be expanded beyond the family level to the community so as to ensure that persons with Down syndrome become able to understand and reach their full potential, with their communities and country lifting them up further.⁶⁶This study focused on the awareness or appreciation of Down syndrome in Uganda as such, it helped in identifying the barriers to inclusion of people with Down syndrome in Uganda.

Gelaro, Amana, SieWhitten, Van Leeuwen, Lindstrom, Karrel, and Pinckney established that barriers to inclusion of individuals with Down syndrome include; discrimination and stigmatization due to lack cultural of cultural awareness, lack of specialized medical care and alienation from the education the system.⁶⁷ They recommended advocacy, medical training of midwives to ensure earlier diagnosis of Down syndrome, providing care for commonly occurring co-morbidities, creating inclusive education opportunities by increasing teachers training and coordination and collaboration among the key stakeholders as the best way to remedy those vices.⁶⁸This study sought to map available resources, identify gaps in medical care and education, and describe the unique challenges facing children and adults with Down syndrome in Uganda this study provided a relevant guide in identifying challenges which people with Down syndrome are facing and recommendations on what should be done to ensure inclusion and resilience among people with Down syndrome in Uganda.

1.11.7 Challenges that caregivers of people with Down syndrome are facing in Uganda.

A study Conducted by Alshatti found out that caregivers of people with Down syndrome struggled to accept the diagnosis of their children with DS, caring for them and discrimination in schools and communities. The study recommended improvement of availability of specialized services, delivery of guidance and counselling, and social integration as the best way to overcome

⁶⁵ Sullivan (n 41) 2-3.

⁶⁶ Ibid 5.

⁶⁷Gelaro (n 36) 87-90.

⁶⁸ Ibid.

challenges associated with raising a person with Down syndrome.⁶⁹ Much as this study discusses the challenges which care givers of people with Down syndrome face, it does not reflect the challenges in Uganda and it should be noted that at the time of conducting this research there was no literature which addressed challenges that care givers of people with Down syndrome in Uganda have been facing which this study sought to address.

1.11.8 Practices that have been adopted by other jurisdictions in promoting inclusion of people with Down syndrome.

Kamau Otube, Nzoka notes that in bid to promote inclusion of people with Down syndrome in Kenya, Kenya has ratified the CRPD,⁷⁰ the ACHPR and Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa which to guarantee right of persons with disabilities⁷¹ and has incorporated the provisions of those instruments in its Constitution and the People with Disabilities Act which provides for inclusion of people with Down syndrome.⁷²

The Ministry of Public Service Gender Senior Citizens Affairs and Special Programmes on the other hand notes that in bid to promote inclusion of people with disability, Kenya developed and launched the Disability Awareness Creation Booklet and Disability Mainstreaming Strategy. That it has also ratified the Protocol to the African Charter on Humana and Peoples Rights on Rights of Persons with Disabilities in Africa, established 243 Community-Based Rehabilitation (CBR) sub committees at sub-county level, supported sensitization of over 70 private sector companies, organized a national-level webinar bringing together 100 persons with disabilities their

⁶⁹Amna AlShatti, Dana AlKandari, Hessa AlMutairi, Dalal AlEbrahim, Abdullah AlMutairi, Danah AlAnsari, Lulwa Abduljaleel, Hassna AlEnzi, Latifa AlFoudari, Hamad AlShaib, Khalid AlAzmi and Jamil Ahmed Caregivers' Perceptions and Experience of Caring for Persons with Down Syndrome in Kuwait: A Qualitative Study' (2021) IJDD 4-6 <www.researchgate.net/publication/350854585_Caregivers'_perceptions_and_experience_of_caring_for_persons_with_Down_syndrome_in_Kuwait_a_qualitative_study/link/60768d3c299bf1f56d561c4a/download> accessed 10 February 2023.

⁷⁰ Ibid.

⁷¹ ACHPR art 2 and art 28.

⁷² Kamau Lydia Wanjiku, Nelly Otube and Stephen Nzoka, 'Academic Achievement of Learners with Down Syndrome in Special Primary Schools for Learners with Intellectual Disability in Kiambu County, Kenya' (2022) 12(4) IJSRP 328 <www.ijsrp.org/research-paper-0422/ijsrp-p12447.pdf> accessed 11 February 2023.

representative OPDs, development partners, Government,⁷³has invested approximately Ksh. 103.75 million in promoting inclusive education ⁷⁴ and has developed economic empowerment programme that has provided grants to self-help groups and individual members and offered entrepreneurship skills training.⁷⁵It should however be noted that all those programs were developed to promote inclusion of people with disability in general not people with Down syndrome specifically which this study sought to remedy.

1.11.9 Conclusion

Much as there is numerous literature which discusses inclusion of people with disability, none of them relates implementation of those legal and policy frameworks to the mental health of people with Down syndrome and their care givers which this study sought to address.

⁷³ Ministry of Public Service Gender Senior Citizens Affairs and Special Programmes, 'Status Report on Disability Inclusion in Kenya, 2021: Implementation of the Global Disability Summit Commitments of 2018' (2021) 7< www.socialprotection.go.ke/wp-content/uploads/2022/03/STATUS-REPORT-ON-DISABILITY-INCLUSION-IN-KENYA-2021.pdf> accessed 13 February 2023.

⁷⁴ Ibid.

⁷⁵ Ibid.

CHAPTER TWO

2.0 The Laws that Provide for Inclusion of people with Down syndrome in Uganda.

2.1 Introduction

Uganda is a signatory to a number of key pieces of legislations which provides for inclusion of people with Down syndrome ranging from the international level to the national level. This chapter provides a discussion of the legal regime on inclusion of people with Down syndrome in Uganda.

2.2 International Legal Framework on Inclusion of People with Down syndrome.

2.2 .1 United Nations (UN) Declaration of Human Rights (1948)

The UDHR is the basis of every human right document. It provides that all people are free and equal in rights and dignity.⁷⁶ As such, even people with Down syndrome have the same rights as everyone else just by virtue of being human. It is relevant to note that the UDHR in itself is not a legally binding instrument, nevertheless, it establishes a fundamental set of human rights that applies to all nations.⁷⁷

2.2.2 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

Uganda is a signatory to the UN Convention on the Rights of Persons with Disabilities⁷⁸ which was adopted on December 13, 2006 by the UN General Assembly⁷⁹ to promote, protect and ensure full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity.⁸⁰

⁷⁶Universal Declaration of Human Rights (adopted 10 December 1948 UNGA Res 217 A (III) (UDHR) art 1.

⁷⁷ Carla Arena Ventura . 'International Law, Mental Health And Human Rights'(2014) University Of São Paulo 1.

⁷⁸ Ministry of Gender, Labour and Social Development (n 37) 114.

⁷⁹ Steven J Hoffman, Lathika Sritharan and Ali Tejpar , 'The Un Convention on the Rights of Persons with Disabilities and Its Impact on Mental Health law and Policy In Canada' (2016) LMMHLPC, 54 <www.researchgate.net/publication/321330020_The_UN_Convention_on_the_Rights_of_Persons_with_Disabilities_and_its_Impact_on_Mental_Health_Law_and_Policy_in_Canada> accessed 7 February 2023.

⁸⁰ Convention on the Rights of Persons with Disabilities (adopted on 13 December 13, 2006, entered into force May 3, 2008), 2515 UNTS 3 art. 1.

The rights enshrined under this Convention include; civil and political rights like the right to liberty,⁸¹ right to integrity of the person,⁸²right to freedom of expression,⁸³right to privacy,⁸⁴ right to freedom from torture and inhuman treatment,⁸⁵ right to equal recognition before the law⁸⁶and right to access to justice.⁸⁷It also include economic, social and cultural rights like the right to home and family life,⁸⁸ right to education,⁸⁹ right to health⁹⁰ and to habilitation and rehabilitation.⁹¹ In addition to the above, it also provides for some specific rights like the right to non-discrimination,⁹² right to independent living and community inclusion⁹³ to work and employment ⁹⁴to participation in cultural life ⁹⁵ and to be free from exploitation and abuse.⁹⁶

Uganda as a signatory to this convention has a duty to modify or abolish existing discriminatory laws, regulations and practices as well as to provide programs to support CRPD rights⁹⁷through providing training on disability issues to those involved in the administration of justice, ⁹⁸putting in place programs to recognize and combat exploitation,⁹⁹ providing community support services ¹⁰⁰ raising awareness on disability issues¹⁰¹and combating discrimination. ¹⁰²

⁸¹ Ibid art 14.

⁸²Ibid art 17.

⁸³ Ibid art 21.

⁸⁴ Ibid art 22.

⁸⁵ Ibid art 15.

⁸⁶Ibid art 12.

⁸⁷ Ibid art 13.

⁸⁸ Ibid art.23.

⁸⁹Ibid art 24.

⁹⁰ Ibid art 25.

⁹¹Ibid art 26.

⁹²Ibid art 5.

⁹³ Ibid art 19.

⁹⁴ Ibid art 27.

⁹⁵ Ibid art 30.

⁹⁶ Ibid art 16.

⁹⁷ Ibid art 4.

⁹⁸ Ibid art 13.

⁹⁹Ibid art 16.

¹⁰⁰ Ibid art 19.

¹⁰¹ Ibid art 8.

¹⁰² Ibid art 5.

The CRPD recognizes that every person with disabilities have a right to respect for his or her physical and mental integrity on an equal basis with others.¹⁰³

In addition to the CRPD, Uganda has also ratified its Optional Protocol which empowers individuals to submit complaints against the State alleging violations of CRPD to the UN Committee on the Rights of Persons with Disabilities¹⁰⁴ and it enables the Committee to follow up on potential violations.¹⁰⁵

The General Assembly has also adopted the Standard rules on the equalization of opportunities for persons with disabilities containing a broad range of commitments to ensure that equal opportunities are available to persons with disabilities in all fields. The rules contain principles regarding responsibility, action and cooperation with respect to: healthcare, policymaking, rehabilitation, support services, raising awareness, employment, family life, education and legislation.¹⁰⁶

2.3 Regional Legal Framework on inclusion of people with Down syndrome

2.3.1 The African Charter on Human and Peoples' Rights, 1981

At the regional level, Uganda is member of the African Union¹⁰⁷ and it has ratified the African Charter on Human and People's Rights (also known as the Banjul Charter) which came into force on 21st October 1986.¹⁰⁸ This Charter was put in place to promote the different human rights and freedoms that accrue to the African people who are bound together in part by their shared history.¹⁰⁹

¹⁰³ Ibid art. 17.

¹⁰⁴ International Justice Resource Center, 'Country Factsheet Series' (International Justice Resource Center, 15 September 2017) 2 < <https://ijrcenter.org/wp-content/uploads/2017/11/Uganda.pdf> > accessed 7 February 2023..

¹⁰⁵ Hoffman (n 79) 56.

¹⁰⁶ Miriam Wachira and Doug Cassell, 'The Interpretation of the Right to Mental Health in the Africa and American Systems' (2018) 2 Africa Human Rights Yearbook ,228< <http://doi.org/10.29053/2523-1367/2018/v2n1a10> > accessed 7 February 2023

¹⁰⁷ International Justice Resource Center (n 104).

¹⁰⁸ Uganda ratified it on 10th May, 1986< <http://www.achpr.org/states/uganda/ratifications/>> accessed 7th February 2023.

¹⁰⁹ African Charter on Human and Peoples' Rights (adopted 27 June 1981, entered into force 21 October 1986) (1982) 21 ILM 58 (African Charter), Preamble.

This charter guarantees the people living with Down syndrome the right to equality,¹¹⁰ rights to enjoy the best attainable state of physical and mental health,¹¹¹ and a right to special measures of protection in keeping with their physical or moral needs.¹¹² This charter expresses acknowledgement of the rights of disabled people not merely to be free from discrimination but to be entitled to all services equally.¹¹³

It is important to note that the legal provisions are irrelevant unless they are put into action however this is not yet the case in Africa as many of the disability legislations are left over from the colonial era with few rights and protections that are required by modern international law coupled with minimal service provision based in an institutional setting.¹¹⁴ As such, even with WHO's advice to African governments on legal and service reforms may be impossible due to lack of financial and professional resources.¹¹⁵

The most important document ensuring inclusion of and resilience among persons with Down syndrome is the 2018 Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, which was adopted at the thirtieth ordinary session of the Assembly of the African Union in Addis Ababa on 29th January 2018.¹¹⁶ Since Uganda has not adopted the protocol it is irrelevant to discuss it.

¹¹⁰ Ibid art 2 and art 28.

¹¹¹ Ibid art 161.

¹¹² Ibid art 18(4).

¹¹³ Peter Bartlett and Vanja Hamzic, 'Reforming Mental Disabilities law in Africa :Tips and Suggestions' (2010) Human Rights Law Center 4

<www.researchgate.net/publication/265427977_2010_REFORMING_MENTAL_DISABILITY_LAW_IN_AFRICA_PRACTICAL_TIPS_AND_SUGGESTIONS> accessed 7 February 2023.

¹¹⁴ Ibid.

¹¹⁵ Ibid.

¹¹⁶ Agata Szwed, 'Protection of Persons with Mental Disorders in Public International Law – A Regional Model' (2021) 24 (4) ERSJ 1052.

2.4 The National Legal Frame Work which provides for inclusion of people with Down syndrome.

2.4.1 The Constitution of the Republic of Uganda (1995).

The Constitution of the Republic of Uganda was adopted on 22nd September 1995 by the Constituent Assembly¹¹⁷ and it entered into force on 8 October 1995.¹¹⁸ The Constitution of the Republic of Uganda of 1995 is the overriding national legal framework for ensuring that rights of persons with disabilities are protected. It prohibits discrimination of people on the basis of disability¹¹⁹ and grants equality to everyone in all spheres of life.¹²⁰

The Constitution further guarantees persons with disabilities a right to respect and human dignity and puts on the State and society the duty to take appropriate measures to ensure that people with disabilities realize their full mental and physical potential.¹²¹

The Constitution also put on the state the duty to enact laws and develop policies that address the concerns of the people with disabilities,¹²² to provide for fair representation of disabled people on all constitutional and other bodies,¹²³ to take affirmative action to redress the imbalances that exist against persons with disabilities¹²⁴ and ensure that the parliament makes appropriate laws for the establishment of an equal opportunities commission and protection of Persons with Disabilities.¹²⁵

Pursuant to article 37 of Constitution of Uganda, the parliament enacted the Equal Opportunities Act, the Children's Act 2016 and the person with Disability Act 2020 which constitute the legal regime on inclusion of people with Down syndrome in Uganda.

¹¹⁷ConstitutionNet, 'The Constitutional History of Uganda' <<http://constition.org/country/constitutional-history-uganda>> accessed 8 February 2023.

¹¹⁸ The Constitution of the Republic of Uganda of 1995 as amended (The 1995 Constitution).

¹¹⁹ Ibid art 21(2).

¹²⁰ Ibid.

¹²¹ Ibid art 35.

¹²² Ibid Objective xvi.

¹²³ Ibid Objective vi.

¹²⁴ Ibid art 32(1).

¹²⁵ Ibid art 35(2).

2.4.2 Persons with Disability Act (2020)

The Persons with Disabilities Act 2020 was assented to on 19 September 2019 but it commenced on 14 February 2020. ¹²⁶This Act domesticates the Convention on the Rights of Persons with Disabilities (CRPD) and it's the principal legislation which guarantees persons with disabilities the right to equality and non-discrimination. ¹²⁷It was enacted to provide for the respect and promotion of the fundamental and other human rights and freedoms of persons with disabilities; to re-establish the National Council for Disability as the National Council ¹²⁸to provide for the local government councils for persons with disabilities; to repeal the Persons with Disabilities Act, the National Council for Disability Act.¹²⁹

To operationalize the Persons with Disabilities Act 2020 (PWDA), the government of Uganda initiated the formulation of Regulations which are now pending approval by Government.¹³⁰

This PWDA defines disability as a substantial functional limitation of a person's daily life activities caused by physical, mental or sensory impairment and environment barriers, resulting in limited participation in society on equal basis with others.¹³¹ Further, it categorizes disability to include learning disability¹³²like Down syndrome and also guarantees people with Down syndrome rights and freedoms which include; respect and promotion of rights and freedoms like right to equality in the provision of education services, health services, employment, affirmative action, information and training.¹³³

It also recognizes disability as a crosscutting issue that transcend all sectors and requires all stakeholders to use the policy as a framework for guiding planning, resource allocation and

¹²⁶ National Union of Disabled Persons, ` Individual Non-Governmental Organizations Submission to the Universal Periodic Review :40th Session of the UPR Working Group-the United Nations Human Rights Council On The Republic Of Uganda '(Individual Submission ,15th July 2021) 3 < https://www.upr-info.org/sites/default/files/documents/2022-01/js40_upr40_uga_e_main.pdf > accessed 7 February 2023.

¹²⁷ Ibid.

¹²⁸ Ibid 5.

¹²⁹ PWDA 2020, long title.

¹³⁰ National Union of Disabled Persons (n 126).

¹³¹ PWDA 2020, s 1(1).

¹³² Ibid schedule 3.

¹³³ PDWA 2020, Part 2.



implementation of interventions in an inclusive manner.¹³⁴ It should however be noted that even if this law prohibit discrimination against persons with disabilities, the government does not effectively enforce this law as the existing human rights bodies do not have the requisite powers to address many of the issues raised in addition to lack of assistance and support in courts.¹³⁵

This Act also re-establishes the National Council for Persons with Disabilities, the District Council for Persons with Disabilities, and the Sub-County Councils for Persons with Disabilities and spells out the composition of these Councils as well as clarifies issues around stipends.¹³⁶

Much as the PWDA it's the principal legislation which provides for inclusion of people with Down syndrome, it has been criticized for being vague since it provides for very lenient criminal penalties for non-compliance with serious elements of the Act.¹³⁷

2.5 Conclusions

Uganda has ratified several instruments both at the international and regional level and has also enacted Persons with Disabilities Act 2020 which provide a legal framework for inclusion of people with disabilities which applies to people with Down syndrome as well. It is important to note that due to lack regulations to guide their implementation these laws are still inoperative.

¹³⁴ Inclusive Futures, 'Ukaid Development initiative, 'Uganda's disability data landscape and the economic inclusion of Persons with Disabilities' (2021)7.

¹³⁵ Ministry of Gender, Labour and Social Development (n 37).

¹³⁶ Ibid Part 3.

¹³⁷Development Initiatives (n 61).

CHAPTER THREE

3.0 Barrier to inclusion of people with Down syndrome in Uganda

3.1 Introduction

Despite having a strong legal framework which provides for inclusion of people with Down syndrome,¹³⁸ people living with Down syndrome in Uganda are still facing exclusion in communities, schools, health care systems and employment due to the existence of several factors which hinder their inclusion. This chapter discusses the barriers to inclusion of people with Down syndrome in Uganda.

3.2 Discriminative Cultural Beliefs

Although Uganda has an active history of disability activism and legislation specific to disability, societal and negative cultural attitudes and perceptions have been indicated as the greatest obstacle to disability inclusion.¹³⁹ In Uganda, individuals with Down syndrome are perceived as a curse or a lifelong financial and social burden to their families.¹⁴⁰ The communities associate Down syndrome with witchcraft and curses; they believe that a child born with Down syndrome is a result of maternal misdeeds or that the child is connected with the evil world.¹⁴¹ Due to this misconception, children with DS face alienation in their communities as they are often segregated from peers.¹⁴² Further, mothers of children with disabilities are blamed and divorced for their child's disability since it is viewed as a punishment for past bad behavior¹⁴³ as a result, they are left alone to raise their disabled children. On the other hand, the children are kept from the outside world for fear of the shame as such, they are stigmatized, discriminated and neglected by the society.¹⁴⁴

¹³⁸ Julie Abimanyi-Ochom, Hasheem Mannan, 'Uganda's disability journey: Progress and Challenges' (2014) 3(1) AJD 108.

¹³⁹ Sullivan (n 41) 4.

¹⁴⁰ Mariam Namasaba, Neo Kazembe, Georgina Seera and Ali Ayub Baguwemu, 'Broadening the Scope Of Social Support, Coping Skills and Resilience Among Caretakers of Children with Disabilities in Uganda: A Sequential Explanatory Mixed-Methods Study' (2022) 22 BMC Public Health 22 (690).

¹⁴¹ Sullivan (n 41) 2-3.

¹⁴² Gelaro (n 36) 84.

¹⁴³ Ibid.

¹⁴⁴ Sullivan (n 41) 2-3.

3.3 Lack of awareness about Down syndrome among the Communities

Lack of awareness about Down syndrome is still rampant among the Ugandan Communities. It was reported that there is no specific word for Down syndrome in Luganda.¹⁴⁵ This is because the medical professionals and community health workers use the English term Down syndrome and that due to lack of education and cultural awareness the community refer to people with Down syndrome with demeaning names such as 'stupid' or 'unable or mad'.¹⁴⁶ It was further reported that those names have promoted discrimination and has supported the misconception that individuals with Down syndrome are less than their peers and are not valued members of the community¹⁴⁷ not only in communities but also at hospitals, schools and work places.

3.4 Lack of Medical Care for people with Down syndrome

Another barrier to inclusion of people with DS is lack of equipment's to be used to diagnose people with Down syndrome in Uganda in addition to fact that a portion of health workers or midwiferies have not been formally trained to identify Down syndrome which has led to diagnosis of children with the congenital malformation until childhood.¹⁴⁸

It was reported that the blood test necessary to confirm the presence of trisomy 21 called karyotyping requires a machine many small clinics do not have and is unaffordable for the average family in Uganda¹⁴⁹ since medications and services that are available free of charge through the UNMHCP does not include treatment for conditions associated with Down syndrome.¹⁵⁰ As such, early and clear diagnosis are often not done and key pediatric care considerations go unchecked for years, which are detrimental to the child's future development and health.¹⁵¹

In addition to the above, it was reported that many of the recommended medical screenings and specialized care procedures are limited to urban areas with few specialists to address the health needs of people with Down syndrome in Uganda and that international travel are too costly for the

¹⁴⁵ Gelaro (n 36) 84.

¹⁴⁶ Ibid.

¹⁴⁷ Ibid.

¹⁴⁸ Sullivan (n 41) 3.

¹⁴⁹ Gelaro (n 36) 88.

¹⁵⁰ Ministry of Gender, Labour and Social Development (n 37) 140.

¹⁵¹ Gelaro (n 36) 88.

average family as a result, individuals with the Down syndrome often go without care¹⁵²which possess a great danger to their lives.

3.5 Lack of training of teachers to provide special needs education

Research shows that schools in Uganda lack special needs education professionals trained to address the unique learning needs of children with Down syndrome,¹⁵³consequently the unique educational needs of children with Down syndrome remain unmet as there are few educators with the necessary expertise and resources to individualize education plans.¹⁵⁴ In addition to the above, the available curriculum is not modified and adapted to be developmentally appropriate or accessible to a child with Down syndrome as a result most of children with Down syndrome do not graduate or advance from Primary 1 class to Primary 2 due to poor performance and thus they repeat Primary 1 until they are of age for vocational training.¹⁵⁵

3.6 Lack of records of deliveries

It was reported that in Uganda an expansive number of deliveries occur in non-traditional health centers such as birthing homes or religious centers and that such institutions do not keep records of births or formal statistics of children born with disabilities.¹⁵⁶ It was also reported that even local community clinics or government maternity centers have difficulty in maintaining accurate records¹⁵⁷and that the last national census was conducted in 2014. This has made monitoring and targeting of disability related goals inefficient given the extensive time lag in such surveys and the rapid changes in living with Down syndrome in all domains of life and across life span.¹⁵⁸

¹⁵² Ibid.

¹⁵³ SESRIC, ` Employment Situation of People with Disabilities in Uganda: Prospects and Challenges '(Employment of Persons with Disabilities Istanbul (From 26th -28th OOctober 2016) <www.sesric.org/imgs/news/1474_Uganda.pptx> accessed 21 February2023.

¹⁵⁴Gelaro (n 36) 88.

¹⁵⁵ Ibid.

¹⁵⁶ Ibid.

¹⁵⁷Ibid.

¹⁵⁸Ibid.

3.7 Conclusion

Much as the government of Uganda has created laws addressing inclusion of people with Down syndrome, the major setback lies in implementing and enforcing those policies¹⁵⁹as the government relies on non-governmental organizations to implement and monitor policy yet there are only a few NGO advocacy groups with this capacity and the government resources to support these initiatives are scarce.¹⁶⁰As result, people living with Down syndrome are still being excluded in communities, schools, health care system and work places.

¹⁵⁹ OHCHR , 'Committee on the Rights of Persons with Disabilities Considers Report of Uganda' (OHCHR ,08 April 2016)< www.ohchr.org/en/press-releases/2016/04/committee-rights-persons-disabilities-considers-report-uganda> accessed 15 February 2023.

¹⁶⁰ Gelaro (n 36) 89.

CHAPTER FOUR

4.0 Analysis of the Approaches which were adopted by other Jurisdictions in promoting inclusion of people living with Down syndrome.

4.1 Introduction

Under the CRPD, state parties have a duty to put in place appropriate measures to ensure inclusion of people with disabilities in education,¹⁶¹health care¹⁶²community¹⁶³ and employment.¹⁶⁴Uganda as a state party to the CRPD has put in a number of laws and policies to promote inclusion of people with disabilities, however, their implementation were limited to other forms of disabilities not Down syndrome. It was therefore relevant to analyze approaches which were adopted by other jurisdictions in this regard.

The jurisdictions which were analyzed include; Canada and Kenya because they are parties to the CRPD and have best approaches on inclusion of people with disabilities which Uganda could borrow a leaf. However, this discussion focused on inclusion in employment, education, health and communities.

4.2 Canada.

4.2.1 Introduction

In Canada with exception of Quebec, birth prevalence of Down syndrome has been stable in the last decade, averaging 15.8 per 10,000 total births, between 2005 and 2013.¹⁶⁵ The rate of Down syndrome among stillbirths remained relatively stable around 31.2 per 1,000 stillbirths, except for a slight decrease from 2010 to 2012, while the rate among live births remained stable at approximately 13.5 per 10,000 live births between 2005 and 2013.¹⁶⁶The rates of Down syndrome in Canada have not increased proportionately. This is due to increased use of prenatal diagnostic

¹⁶¹Ibid art 24.

¹⁶² Ibid art 25.

¹⁶³ Ibid art 19.

¹⁶⁴ Ibid art 27.

¹⁶⁵ The Public Health Agency of Canada's Canadian Perinatal Surveillance System, 'Down Syndrome Surveillance in Canada, 2005-2013' (2013) 1 <www.phac-aspc.gc.ca/rhs-ssg/> accessed 10 February 2023.

¹⁶⁶Ibid.

procedures followed by terminations of Down syndrome pregnancies.¹⁶⁷ The rates of terminations due to Down syndrome vary widely across Canada potentially due to differences in access to prenatal screening/pregnancy termination and attitudes of women towards terminating the pregnancy once the diagnosis has been made.¹⁶⁸

In Canada, people with Down syndrome are protected as people with disability other than mental illness. Canada is party to the UN Convention on the Rights of Persons with Disabilities (CRPD) which it ratified on 11 March 2010 during the Vancouver Winter Olympics.¹⁶⁹ The government of Canada has not enacted any implementing legislation, although some aspects of the CRPD like the right to life¹⁷⁰ and the right to freedom from torture or cruel, inhuman, and degrading treatment¹⁷¹ automatically constitute Canadian domestic law unless contradictory legislation has been enacted.¹⁷² Nevertheless, it has been urged that the existing legislation implicitly implements the CRPD in the absence of implementing legislation and that while this argument may be plausible in other domains, it may not be applicable in the immigration law.¹⁷³

It was urged that the implementation of CRPD in Canada is hindered by Canada's reservations to Article 12 of the CRPD support of substitute decision-making" regimes. This means that many Canadians with mental health challenges continue to be denied legal capacity to make decisions related to their healthcare, housing, and finances. However, the introduction of new legislation in the different jurisdictions across the country and recent court decisions have started to push policymakers in this direction.¹⁷⁴ With Canada's agreement to follow the Optional Protocol in

¹⁶⁷Ibid 3.

¹⁶⁸Ibid.

¹⁶⁹Ravi A Malhotra, 'The Impact of the Convention on the Rights of Persons with Disabilities on Canadian Jurisprudence: The Case of Leobrero v. Canada' (2017) 54(3) ALR 637, 644 <<https://canlii.ca/t/6rd>> accessed 11 February 2023.

¹⁷⁰ CRPD art 10.

¹⁷¹ Ibid art 15.

¹⁷² Malhotra (n 169).

¹⁷³ Ibid.

¹⁷⁴ Ali Tejpar, Steven J. Hoffman and Lathika Sritharan, 'The UN Disability Treaty's Impact on Mental Health Law And Policy in Canada(2016)< <https://blogs.biomedcentral.com/bmcseriesblog/2016/12/07/the-un-disability-treatys-impact-on-mental-health-law-and-policy-in-canada/>> accessed 11 February 2023.

2018, people in Canada can make complaints to the United Nations Committee on the Rights of Persons with Disabilities on any violations of the CRPD.¹⁷⁵

In Canada, disability laws are provincially regulated through 13 different acts across the 10 Canadian provinces and 3 territories. The legislation at the provincial level can create significant variance between laws and strategies however, all those laws must uphold the Canadian Charter of Rights and Freedoms and where it is believed to violate charter rights, laws can be challenged in the Supreme Court of Canada with landmark cases often ushering in new or amended laws and policy reform.¹⁷⁶

4.2 .2. Categorization of Down syndrome under Canadian laws

Under the Canadian law, Down syndrome is categorized as a disability rather than a mental illness¹⁷⁷this is evident in the definition of disability under Accessible Canada Act which defines disability as any mental, intellectual, learning, communication or sensory impairment whether permanent, temporary or episodic which hinders a person’s full and equal participation in society.¹⁷⁸ Since people with Down syndrome suffer from both intellectual and learning disabilities,¹⁷⁹they fall under the above definition.

4.2.3 Rights of people with Down syndrome guaranteed under Canadian laws

The rights of people living with Down syndrome are provided for under different laws including the Canadian Charter of Rights and Freedoms 1982, Accessible Canada Act 2019 and among

¹⁷⁵ARCH Disability Law Center, ‘The Convention on the Rights of Persons with Disabilities (CRPD) and the Optional Protocol ‘(ARCH Disability Law Center, 21 November 2019)2 <<https://archdisabilitylaw.ca/wp-content/uploads/2019/11/Fact-Sheet-CRPD-and-Optional-Protocol-Nov-21-2019-1.pdf>> accessed 11 February 2023.

¹⁷⁶Theodore D Cosco , C. Randa , S Hopper , K R Wagner , J. Pickering and J. R. Best, ‘Ageing and Mental Health in Canada: Perspectives from Law, Policy, and Longitudinal,’(2022) 15 RJP , 865 < <https://doi.org/10.1007/s12062-022-09389-z>.> accessed 6 February 2022.

¹⁷⁷ Mark Christopher Weber, ‘The Bigger Barrier to Immigration, (2016) Winnipeg Free Press 7.

¹⁷⁸Accessible Canada Act 2019 (CA) s 2.

¹⁷⁹ Whites Wan Foundation , ‘Neurodevelopmental Disorders Learning Disability’ (23 January 2015) <www.whiteswanfoundation.org/disorders/neurodevelopmental-disorders/learning-disability > accessed 6 March 2023.

others. The Canadian Human Rights Act provides that people with disabilities have a right to be free from discrimination and harassment on ground of disability in five social areas: housing, employment, goods, services and facilities, contracts and membership in unions, trade and professional associations.¹⁸⁰ Further, the Charter grants people with Down syndrome the right to life, liberty and security of the person,¹⁸¹ protection against arbitrarily detentions and imprisonment,¹⁸² right to equal protection under the law and equal benefit of the law.¹⁸³ However, the detail analysis was limited to inclusion of people with Down syndrome socially, economically, in education and health care.

4.2.3.1 Economic inclusion of people with Down syndrome

In Canada, there is no employment policy which specifically focuses on inclusion of people with Down syndrome in employment, consequently, the employment of people with Down syndrome are governed under the Employment Equity Act¹⁸⁴ which seeks to achieve equality in the workplace by removing barriers to employment for designated groups, including persons with disabilities; to correct the conditions of disadvantage in employment for the designated groups; and to give effect to the principle that employment equity means more than treating people in the same ways.¹⁸⁵

Further, the Western Economic Diversification Act¹⁸⁶ provides for Entrepreneurs with Disabilities Program which enables Western Canadians with Down syndrome to access a network of business

¹⁷⁹ Gregorio Katz and Eduardo Lazcano-Ponce, 'Intellectual Disability: Definition, Etiological Factors, Classification, Diagnosis, Treatment and Prognosis' (2008) 50(2) SPM 133.

¹⁸⁰ Canadian Human Rights Act 1985 (CA) s 3.

¹⁸¹ Canadian Charter of Rights and Freedoms 1982 (CA) s 7.

¹⁸² Ibid s 9.

¹⁸³ Ibid s 15.

¹⁸⁴ Employment Equity Act 1995 (CA).

¹⁸⁵ Mary Ann McColl, Atul Jaiswal, Shannon Jones, Lynn Roberts, Caitlin Murphy, 'A Review of Disability Policy in Canada' (2017) Canadian Disability Policy Alliance 24 <www.disabilitypolicyalliance.ca/wp-content/uploads/2018/01/A-Review-of-Disability-Policy-in-Canada-3rd-edition-Final-1-1.pdf> accessed 19 February 2023.

¹⁸⁶ Western Economic Diversification Act 1985 (CA).

Professionals and a world of resources.¹⁸⁷The program provides business information, training and development, mentoring and one-on-one counselling service to entrepreneurs who are seeking to start up or expand a small or medium-sized business.¹⁸⁸

In addition to the above, the Opportunities Fund for Persons with Disabilities under the Department of Employment and Social Development Act¹⁸⁹ provides funding for organizations to help people with disabilities prepare for, obtain and maintain employment or self-employment.¹⁹⁰The Fund program offers funding for local, regional and national projects to provide and improve employment services and increase the labor market participation of people with disabilities across Canada.¹⁹¹ It has however been established that 75%-80% of people with intellectual disability in Canada are either unemployed or underemployed¹⁹²and that those working, the average income is less than half that of Canadians without a disabilities¹⁹³ and that the Disability Tax Credit currently provides tax relief for just one-third of working-age Canadians with severe and very severe disabilities yet for most of the 750,000 working-age people with severe and very severe disabilities the Disability Tax Credit is of limited assistance because their income and earnings are too low to be taxable.¹⁹⁴

4. 2.3.2 Education inclusion of people with Down syndrome

Basing on the available data, there is no education policy which specifically focuses on the education of people with Downs Syndrome in Canada. The government of Canada gives the Severe Permanent Disability Benefit under the Canada Student Financial Assistance Act.¹⁹⁵This benefit

¹⁸⁷ McColl (n 185) 24.

¹⁸⁸ Ibid.

¹⁸⁹ Department of Employment and Social Development Act 2005 (CA).

¹⁹⁰ McColl (n 185).

¹⁹¹ Ibid.

¹⁹² Canadian Association for Community Living, 'Promote Health & Well-being' (2019) Federal Election 4

<https://inclusioncanada.ca/wpcontent/uploads/2019/09/2019_Federal_Election_Strategy_Supporting_Docs.pdf> accessed 19 February 2023.

¹⁹³ Ibid 4.

¹⁹⁴ Ibid 5.

¹⁹⁵ Canada Student Financial Assistance Act 1994 (CA).

allows for the forgiveness of Canada Student Loans for persons who have severe permanent disability and are experiencing hardship repaying their loans due to disability. The Act refers to all obligations of a borrower in respect of a loan made under the Act, on the basis of the borrower's severe permanent disability which has made him or her unable to repay the loan and will never be able to repay it.¹⁹⁶

Under the same Act, the government also gives the Canada Student Grant for Students with Permanent Disabilities where students with permanent disabilities may receive a specified amount of money per academic year to help cover the costs of accommodation, tuition, and books in the studies (including undergraduate and graduate levels).¹⁹⁷ Another grant is the Canada Student Grant for Services and Equipment for Students with Permanent Disabilities, under the Canada Student Financial Assistance Act, which provides up to a specified amount in non-repayable assistance per academic year for students with permanent disabilities for exceptional education-related services or equipment, such as tutors, note-takers, interpreters, braille's or technical aids.¹⁹⁸

Further, under Canada Student Loans Act ¹⁹⁹a guaranteed student loan can be repaid where the borrower by reason of severe permanent disability is unable to pay and will never be able to repay the loan.²⁰⁰ Research shows that many provinces and territories have not updated their special education policies in over 10 years consequently not all inclusive education policies are up-to-date with current educational standards, or with the international covenants of which Canada is a signatory.²⁰¹

¹⁹⁶ McColl (n 185)27.

¹⁹⁷ Ibid.

¹⁹⁸ Ibid.

¹⁹⁹ Canada Student Loans Act 1985(CA).

²⁰⁰ McColl (n 185)27.

²⁰¹ Helena Towle , 'Disability and Inclusion in Canadian Education Policy, Procedure, and Practice' (2015) Canadian Centre for Policy Alternatives 12

<https://policyalternatives.ca/sites/default/files/uploads/publications/National%20Office/2015/07/Disability_and_Inclusion_in_Education.pdf> accessed 20 February 2023 .

4. 2.3.3 Health care inclusion of people with Down syndrome.

In Canada the treatment benefits are only available to Indians and veterans with disabilities as per the Indian Act, RSC 1985 and the Department of Veterans Affairs Act 1985²⁰² as such, Canadians with disabilities struggle to access appropriate health care, and this is especially true for persons with an intellectual and developmental disability. Report shows that in Canada people with intellectual and developmental disability are 3 to 4 times more likely to experience a mental health issue than the general population yet, appropriate mental health services are often unavailable or inaccessible²⁰³ due lack of specialized training required to confidently treat persons with intellectual and developmental disability and the connection between disability and suffering has been so normalized that some medical professionals mistakenly believe that intellectual and developmental disability is in itself the cause of a person's mental health concerns.²⁰⁴

4. 2.1.4 Social inclusion of people with Down syndrome.

Though the Canadian Human Rights Act prohibits discrimination and harassment on ground of disability in five social areas: housing, employment, goods, services and facilities, contracts, and membership in unions, trade and professional associations,²⁰⁵ in Canada, there is no policy which provides for social inclusion of people with Down syndrome specifically. Research revealed that people with disabilities in Canada experience social exclusion like avoiding or excluding disabled individuals from relationships and activities. It was further reported that people with DS face derogatory hurtful remarks and/or uninviting stares from non-disabled individuals who perceive that they are better than them and stereotypically refer to them as 'bums'²⁰⁶ due to existing exclusionary parameters that deny people with DS full participation and enable lack of understanding, awareness and acceptance of the unique presence and perspective that each disabled person brings to relationships and to citizenship possibilities.²⁰⁷

²⁰² McColl (n 181) 5-36.

²⁰³ Canadian Association for Community Living (n 192).

²⁰⁴ Ibid.

²⁰⁵ Canadian Human Rights Act 1985 (CA) s 3.

²⁰⁶ Randy Johner, 'Disability and Poverty: Stories that Resist Attitudinal Barriers to Inclusion' (2013) 2(3) CJDS 47-48 <<https://cids.uwaterloo.ca/index.php/cids/article/view/100/162>> accessed 20 February 2023.

²⁰⁷ Ibid.

Further in 2018, it was reported that Ben Tarr, a board member with the Canadian Down Syndrome Society submitted an application to the International Union for Conservation of Nature to include people living with DS on the 'endangered' lists.²⁰⁸ Although this campaign received a huge support from the public, some of the people with Down syndrome opposed this campaign on the basis that it made them feel like they were being compared to animals however, their concerns were never put into consideration.²⁰⁹

4. 2.3.5 The New development on inclusion of people with disabilities in Canada

In bid to promote inclusion of people with disability, in 2022 Canada launched the first-ever Disability Inclusion Action Plan which aimed at achieving the full and meaningful participation of persons with disabilities in Canada through eradicating social and economic exclusion which were being experienced by of many persons with disabilities in Canada.²¹⁰ This Action Plan, has four initial pillars i.e. financial security, employment, accessible and inclusive communities and a modern approach to disability.²¹¹

The action plans under it include; development of a new Canada disability benefit to reduce poverty and improve the financial security of working-age persons with disabilities,²¹² updating eligibility and improving access to the disability tax credit, helping persons with disabilities find and keep good jobs, helping them advance in their careers or become entrepreneurs and giving support to employers as they develop inclusive work places,²¹³ embedding disability inclusion within ESDC's existing labour market programs, creating a new equitable access to reading program to improve access to alternate format reading materials for persons with disabilities,²¹⁴ implementing of the accessibility strategy for the Public Service of Canada by committing to

²⁰⁸ Desmond Brown, 'Canadian Down Syndrome Society wants People with Disorder put on Endangered' CBC (Toronto, 7 November 2018) <www.cbc.ca/news/canada/toronto/campaign-down-syndrome-endangered-list-1.4896518> accessed 25 February 2023.

²⁰⁹ Ibid.

²¹⁰ Canada's Disability Inclusion Action Plan 2022 (CA) 4 < www.canada.ca/content/dam/esdc-edsc/documents/programs/disability-inclusion-action-plan-2/action-plan-2022/ESDC_PDF_DIAP_EN_20221005.pdf> accessed 25 February 2023.

²¹¹ Ibid.

²¹² Ibid 10.

²¹³ Ibid 12.

²¹⁴ Ibid 13.

hire 5,000 employees with disabilities in the public service by 2025.²¹⁵ This action plan was made to promote inclusion of people with disability in general, as a result, it does not cater for some of the specific needs of people with Down syndrome. It is also biased as it focuses on promoting economic inclusion of people with disabilities rather than promoting social inclusion, creating inclusive education and health care. This has a bearing on inclusion of people with Down syndrome in Canada in education, healthcare and communities.

4.2.4. Conclusion

In conclusion, in Canada there is no specific inclusion policy which is tailored towards inclusion of people with Down syndrome specifically since all the available policies caters for inclusion of people with disabilities in general including the newly launched Action Plan for inclusion of people with disability. Though it is hoped that the new action plan will foster eradication of health, social and economic exclusion of people with Down syndrome in Canada, this action plan focuses more on promoting economic inclusion of people with disabilities more than social inclusion and inclusion in education or health services which has a bearing on people with Down syndrome in Canada. Another pressing concern is that Canadian jurisdictions have maintained their “substitute decision-making” regimes opposed to supported decision-making” regimes.²¹⁶ This means that many Canadians with Down syndrome shall continue to be denied the legal capacity to make decisions related to their healthcare, housing, and finances²¹⁷ regardless of the inclusive changes that has been put in place.

4.3 Kenya

4.3.1 Introduction

In Kenya, it was reported that there are 40,000 people are living with Down syndrome condition, struggling with speech and movement and that about 1 in every 800 children in Kenya are born with Down syndrome.²¹⁸ It has however been reported that many children born with Down

²¹⁵ Ibid 15.

²¹⁶ CRPD art 12.

²¹⁷ Hoffman (n 79).

²¹⁸ Kamau (n 72).

syndrome in Kenya are locked away from the people's glare and fear of the shame they bring to their parents and healthy siblings.²¹⁹

Just like in Canada people living with Down syndrome in Kenya are protected under disability laws. Kenya ratified the CRPD on 19 May 2008, but is yet to sign its Optional Protocol.²²⁰

Kenya has an obligation to protect the rights of people with disability, their property and their treatment and 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."²²¹

In addition to the above, Kenya also ratified the ACHPR on January 23, 1992 and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa. The ACHPR requires states to guarantee right to equality,²²² the right to enjoy the best attainable state of physical and mental health²²³ right to special measures of protection in keeping with their physical or moral needs.²²⁴ In compliance with its obligations under those instruments, the government of Kenya has incorporated the provisions of those instruments in its Constitution and amended the People with Disabilities Act 2003 which provide for inclusion of people with Down syndrome.

4.3.2 Categorization of Down syndrome under the National laws of Kenya.

Under the Kenyan Constitution, disability is defined to include any physical, sensory, mental, and psychological or other impairment, condition or illness that has, or is perceived by significant sectors of the community to have a substantial or long-term effect on an individual's ability to carry out ordinary day-to-day activities.²²⁵ On the other hand, the Person with Disabilities Act 2003 defines disability to mean a physical, sensory, mental or other impairment, including any visual, hearing, learning or physical incapability, which impacts adversely on social, economic or

²¹⁹Ibid.

²²⁰ Ibid.

²²¹ Ibid.

²²² ACHPR art 2 and art 28.

²²³ Ibid art 161.

²²⁴ Ibid art 18(4).

²²⁵The Constitution of the Republic of Kenya 2010 (KY) art 260.

environmental participation.²²⁶ In Kenya people with Down syndrome are considered as people with intellectual disabilities²²⁷ and in reference to the above definition people with Down syndrome are categorized as people with disability.

4.3.3 Rights of people with Down syndrome guaranteed under Kenyan Laws

The rights of people with Down syndrome in Kenya are guaranteed under Article 54 of the Kenyan Constitution.²²⁸ Those rights include, their rights to be treated with dignity and a right to be addressed and referred to in a manner that is not demeaning, a right to have reasonable access to all places, a right to public transport and information, right to access materials and devices to overcome constraints arising from the person's disability²²⁹ in addition to a right to equality and non-discrimination²³⁰ and a right to inherent dignity.

The Kenyan Constitution also recognizes the economic and social rights of people with disabilities including the right to the highest attainable standard of health, education.²³¹ It further mandates the state to take legislative and other measures, including affirmative action programmes and policies designed to redress any disadvantage suffered by individuals because of past discrimination.²³² However, detailed analysis was limited to the right to equality in social, economic, education and health care context.

Just like in Canada, in Kenya there is no specific policy which is tailored towards promotion of inclusion of people with Down syndrome. However, people with Down syndrome benefit from policies that promote inclusion of people with disabilities in general.

4.3.3.1 Economic inclusion of people with Down syndrome

In Kenya, the government has established an Economic Empowerment programme that has provided grants to self-help groups and individual members for economic empowerment and

²²⁶The Persons with Disabilities Act 2003 (KY) s 2.

²²⁷ Eunice Koros and Trizer Njagi, 'Report on the Inclusive Employment of Persons with Intellectual Disabilities in Kenya' (2022) Down Syndrome Society of Kenya 2 <www.ds-int.org/blog/best-practices-in-the-employment-of-persons-with-intellectual-disabilities-a-case-study-of-kenya> accessed 2023 .

²²⁸ The Kenyan Constitution, art 54.

²²⁹ Ibid art

²³⁰ Ibid art 27.

²³¹ Ibid art 43

²³² Ibid art 27(6).

offered entrepreneurship skills training.²³³The Government through the Tools of Trade empowerment program for Persons with Disabilities has provided start-up tool kits to enable employment and wealth creation opportunities in selected sectors.²³⁴ It was however reported that people with Down syndrome in Kenya experience stigmatization and discrimination at schools and workplaces since they have visible characteristics that cannot be concealed and so people stare at them as if they were unusual creatures²³⁵ which has led many of them to quit jobs.

4. 3.3.2 Education inclusion of people with Down syndrome

In 2018, the government of Kenya put in place Sector Policy for Learners and Trainees with Disabilities which has a clear implementation guidelines that captures the aspirations of stakeholders including people with disabilities.²³⁶ However, it was reported this policy suffers from poor implementation due to limited awareness of disability inclusion and the devolved system of government, cascading policy goals.²³⁷

Further, the Government of Kenya has also put up a lot of initiatives with targeted improvement of infrastructure to accommodate trainees and proper placement for trainees with disabilities seeking industrial attachment and it has invested approximately Ksh. 103.75 million (USD 962,936) to promote inclusive education.²³⁸ However, it has been argued that policy in terms of acceptance and inclusion lacks consistent implementation and ²³⁹has a poor monitoring and enforcement structure.²⁴⁰ Further, it was reported that in Kenyan public school system, children with Down syndrome usually attend mainstream schools from where they are put in special units

²³³ Ministry of Public Service Gender Senior Citizens Affairs and Special Programmes (n 73).

²³⁴ Ibid.

²³⁵ Koros (n 227) 12.

²³⁶ Emily Nyariki ,Adrian Sakwa , Sarah Polack, Shaffa Hameed, Tom Shakespeare ,Nathaniel Scherer, Casey Lynn Crow , Mallory Baxter ,Andre Okunzuwa and Kaylee Stewart ‘Disability-Inclusive Education and Employment: Understanding the Context in Kenya, (2023) 11 <<https://mastercardfdn.org/wp-content/uploads/2023/02/Kenya-Full-Report.pdf> >accessed 13 March 2023.

²³⁷ Ibid 12.

²³⁸ Ministry of Public Service Gender Senior Citizens Affairs and Special Programmes (n 69).

²³⁹ Nyariki (n 236).

²⁴⁰ Koros (n 227) 10.

which are not inclusive and most teachers in Kenyan schools aren't specialized in teaching children with Down syndrome.²⁴¹

4. 3.3. 3 Health Care inclusion of people with Down syndrome

The Kenya Health Policy (2014-2030) does not explicitly define persons with disabilities but refers to them in terms of disability-adjusted life-years and the causes of disability as a part that addresses mental health issues guaranteeing access to health services and medical insurance as an aspect which is important in ensuring non-discrimination. However, the policy has no clear budgetary guidelines and makes no mention of budgets for persons with disabilities.²⁴² The health policy acknowledges the need for multi stakeholder involvement in implementation but the level of engagement of persons with disability in health policy development is unclear.²⁴³ This has a bearing on the inclusion of people with Down syndrome in health as well.

4. 3.3.4 Social inclusion of people with Down syndrome

In Kenya, there is no specific policy which is tailored towards promotion of social inclusion of people with Down syndrome, however, people with Down syndrome benefit from policies that promote social inclusion of people with disabilities. In order to promote social inclusion of people with disability, the Kenyan government has developed and launched the Disability Awareness Creation Booklet to guide partners and other actors in raising awareness on disability, to foster respect for the inherent dignity for persons with disabilities and ensure that they live independently and are included in the community.²⁴⁴ It has also developed and launched the Disability Mainstreaming Strategy to ensure mainstreaming of all their policies, legislation and programs, has ratified the Protocol to the African Charter on Human and Peoples Rights on Rights of Persons with Disabilities in Africa and has established 243 Community-Based Rehabilitation

²⁴¹ Kait Bolongaro, 'Special Education in Kenya' (2015) <www.dw.com/en/special-education-for-down-syndrome-students-in-kenya/a-18853385> accessed 14 March 2023.

²⁴² Winnie Khaemba, Ann Kingiri, Joyce Olenja, Sam Wangila, Emily Nyariki, Anderson Kiraithe and Washington Oloo, 'An Analysis of Health and Persons with Disabilities In Kenya' (2017) Policy Brief 003/2017 1<www.udpkenya.or.ke/wp-content/uploads/2020/05/Policy-Brief-on-Health_11.pdf> accessed 20 February 2023.

²⁴³ Ibid 3.

²⁴⁴ Ministry of Public Service Gender Senior Citizens Affairs and Special Programmes (n 73).

(CBR) sub committees at sub-county level to create awareness on disability issues and to promote inherent respect for human rights and inclusion of Persons with Disabilities in society ²⁴⁵

The Kenyan Government has also supported sensitization of over 70 private sector companies to become more disability inclusive and also organized a national-level webinar bringing together 100 persons with disabilities, their representative OPDs, development partners, government. ²⁴⁶ It has however been observed that stigma and discrimination is still a barrier in addressing the education and employment needs of people with disabilities due to culture and household poverty²⁴⁷ and the fact that children with disabilities are often left out when it comes to allocating resources. ²⁴⁸

4.3.4 Conclusion

Just like in Canada, in Kenya there is no specific policy which is tailored towards promotion of inclusion of people with Down syndrome, however, people with Down syndrome benefit from policies that promote inclusion of people with disabilities in general. Though a lot of policies were put in place to ensure inclusion of people with disability in Kenya, people with Down syndrome in Kenya are still experiencing exclusion from employment, communities, education and health services due to lack of awareness and poor implementation of policies as such, the mental health of people with Down syndrome Kenya is still at stake.

4.4 Uganda

4.4.1 Introduction

Just like Canada and Kenya, Uganda is a signatory to the United Nations Convention on the Rights of Persons with Disabilities²⁴⁹ and has ratified its Optional Protocol which empowers individuals to submit complaints against the state alleging violations of CRPD to the UN Committee on the Rights of Persons with Disabilities, ²⁵⁰ and enables the Committee to follow up on potential

²⁴⁵ Ibid.

²⁴⁶ Ibid.

²⁴⁷ Ministry of Public Service Gender Senior Citizens Affairs and Special Programmes (n 73).

²⁴⁸ Nyariki (n 236)26.

²⁴⁹ Ministry of Gender, Labour and Social Development (n 37) 114.

²⁵⁰ International Justice Resource Center (103).

violations.²⁵¹ At the regional level, just like Kenya, Uganda is a member of the African Union²⁵² and has ratified the African Charter on Human and People’s Rights.²⁵³ At the national level, the Constitution, the Equal Opportunities Act, and the Persons with Disabilities Act, the Employment Act Constitutes the legal framework on inclusion of people with Down syndrome.

4.4.2 Categorization of Down syndrome under the laws of Uganda

The Persons with Disabilities Act defines disability as a substantial functional limitation of a person's daily life activities caused by physical, mental or sensory impairment and environment barriers resulting in limited participation in society on equal basis with others.²⁵⁴ Further, this Act categorizes disability to include mental disability including psychiatric disability and learning disability.²⁵⁵ As it was discussed earlier, Down syndrome is associated with intellectual and learning disability as such, it falls within the definition disability in Uganda.

4.4.3 Rights of people with Down syndrome in Uganda

In Uganda, the right of people living with Down syndrome are guaranteed under the Constitution and other disability laws. Those rights include; the right to freedom from discrimination,²⁵⁶ right to equality in all spheres of life,²⁵⁷ right to respect and human dignity,²⁵⁸ right to enjoy family life, freedom from inhuman and degrading treatment, equality in the provision of education services, health services, employment, transport services and commercial services and also a right to rehabilitation for persons with disabilities, right to affirmative action information and training²⁵⁹ and a right to know their rights.²⁶⁰ However, detail analysis was limited to equality in social, economic, education and health care context.

²⁵¹Hoffman (n 79) 56.

²⁵² International Justice Resource Center (n 103).

²⁵³ Uganda ratified it on 10th May, 1986< <http://www.achpr.org/states/uganda/ratifications/>> accessed 7 February 2023.

²⁵⁴ PWDA 2020, s 1(1).

²⁵⁵ Ibid schedule 3.

²⁵⁶ The 1995 Constitution art 21(2).

²⁵⁷Ibid.

²⁵⁸ Ibid art 35.

²⁵⁹ PDWA 2020, Part2.

²⁶⁰Ibid s 58.

Just like in Kenya and Canada, in Uganda there is no specific policy which is tailored towards promotion of inclusion of people with Down syndrome. However, people with Down syndrome benefit from policies that promote inclusion of people with disabilities in general.

4.4.3.1 Economic inclusion of people with Down syndrome

In bid to promote economic inclusion, the government of Uganda put in place the National Employment Policy for Uganda (2011) which recognizes the employment of vulnerable groups including people with intellectual disabilities which is important for both wealth creation and poverty eradication.²⁶¹ Other relevant legislation include; Equal Opportunities Act, the 2006, Employment Act, the 2000 Worker's Compensation Act and the 2008 Business, Technical, Vocational Education and Training Act as well as provisions for quotas and tax incentives under the Persons with Disabilities Act.²⁶² Much as the government has put in place several legal and policy frameworks to ensure employment of people with disability, these policies are ineffective due to poor implementation.²⁶³

The government also provide the Special Grants to person with disabilities which is a grant and loans-based program for specific interest groups, one-off to support groups of persons with disabilities and their caregivers to undertake income generation activities.²⁶⁴ This program was however criticized for providing a one-off lump sum payment and failing to provide recipients with immediate support for health or education expenses unless they sell their assets which many end up doing.²⁶⁵

Further, the five rehabilitation and training centers which are overseen by MGLSD to provide residential vocational training institutions for persons with disabilities were criticized for lack of

²⁶¹ Aida Nanyonjo and Veronica Nankusu, ' Best Practices in the Employment of Persons with Intellectual Disabilities: A Case Study of Uganda' (2022) 11 <www.ds-int.org/blog/best-practices-in-the-employment-of-persons-with-intellectual-disabilities-a-case-study-of-uganda. >accessed 13 March 2023.

²⁶² Ibid

²⁶³ Ibid 10.

²⁶⁴ Ministry of Gender, Labour and Social Development (n 37) 150.

²⁶⁵ Ibid.

resources, having curriculum which are not aligned with wider business practices and poor training due to budget constraints.²⁶⁶

Further, the informal and the formal employment sectors are not welcoming to people with Down syndrome as they are thought to lack the necessary qualifications for the available jobs, to be less productive than people without disabilities and also to be dependent, non-competitive, at times violent with poor interpersonal skills, helpless and that hypersensitive customers (consumers) will react negatively towards them.²⁶⁷

4.4.3.2 Education inclusion of people with Down syndrome

The government of Uganda provides free primary education to every child regardless of his/her status. In 2022, it was reported that the number of children with disabilities accessing all levels of education (pre-primary, primary, secondary) is falling with the transition from primary to secondary school being particularly problematic.²⁶⁸ It was also revealed that there are only 113 Special Needs Education schools across the country not in every district which are mostly run by non-governmental organizations and faith-based organizations since the overall education is only 0.1%²⁶⁹ which have a little thought of the specific needs of children with disabilities despite the policy focus on inclusive education.²⁷⁰

Further, it was reported that in addition to discrimination and lack of funding for school equipment's and lack of inclusive early childhood development programmes, there is lack of special education professionals trained to address the unique learning needs of children with Down syndrome²⁷¹ and that the available curriculum is not modified and adapted to be developmentally appropriate or accessible to children with Down syndrome.²⁷²

²⁶⁶ Ibid 155.

²⁶⁷ Nanyonjo (n 261)11.

²⁶⁸ Ministry of Gender, Labour and Social Development (n 37) 146.

²⁶⁹ Ibid 146.

²⁷⁰ Ibid.

²⁷¹ SESRIC (n 153).

²⁷² Ibid.

4. 4.3. 3 Health Care inclusion of people with Down syndrome

In Uganda, there is no specific policy on inclusive health and most of these services are provided through the Disability Prevention and Rehabilitation section.²⁷³ Further, it is unclear whether persons with disabilities enjoy the same level of access to all healthcare as their peers without disabilities, though evidence suggests not.²⁷⁴ There is also limited disability- disaggregated information collected by the Ministry of Health to measure inclusion of people with disability and what little is included is largely driven by donor priorities, and is not shared between ministries (or other agencies) to improve coordination of service delivery.²⁷⁵ Further, much as there is a National Integrated Early Childhood Development Policy of Uganda, 2016; and associated national Action Plan which targeted all children early identification and assessment and appropriate referral and support, it's still under-resourced despite calls to increase funding.²⁷⁶

There is also lack of equipment's to be used to diagnose people with Down syndrome in Uganda and most of health workers or midwiferies have not been formally trained to identify Down syndrome and subsequently the newborn isn't diagnosed with the congenital malformation until childhood.²⁷⁷ In addition to the above, the medications and services which are available free of charge through the UNMHCP does not include treatment for conditions associated with Down syndrome²⁷⁸ and the five Rehabilitation Centers which are run by MGLSD provide vocational trainings²⁷⁹ rather than physical or mental services as such, people with Down syndrome do not have access to inclusive health services.

4. 4.3.4 Social inclusion of people with Down syndrome

In Uganda, though the Constitution prohibits discrimination on the basis of disability,²⁸⁰ there is no policy which prohibits social exclusion of people with disabilities. It was revealed that due to

²⁷³ Ministry of Gender, Labour and Social Development (n 37) 137.

²⁷⁴ Ibid.

²⁷⁵ Ibid.

²⁷⁶ Ibid.

²⁷⁷ Sullivan (n 36) 3.

²⁷⁸ Ministry of Gender, Labour and Social Development (n 37) 140.

²⁷⁹ Ibid 14.

²⁸⁰ The 1995 Constitution art 21.

lack of education and cultural awareness in the communities individuals with Down syndrome are still perceived as a curse or a lifelong financial and social burden to their families²⁸¹ and associated with witchcraft, maternal misdeeds or the evil world²⁸² and are referred to by demeaning names such as 'stupid' or 'unable or mad'.²⁸³ This has led to stigmatization alienation and segregation of people with Down syndrome in various communities in Uganda.²⁸⁴

4.4.4 Conclusion

Just like in Kenya and Canada, in Uganda, there is no specific policy which is tailored towards promotion of inclusion of people with Down syndrome however, people with Down syndrome benefit from policies that promote inclusion of people with disabilities. Despite having strong legislations on inclusion of people with disabilities, inclusion policies in Uganda are still ineffective due to poor implementation caused by lack of funding and resources. Further, the current policies are inadequate as they do not cater for the specific needs of people with Down syndrome.

4.5 Lessons that Uganda should learn from other jurisdictions in bid to promote inclusion of people with Down syndrome.

Uganda should with appropriate modifications adopt Canada's approach in promoting economic empowerment through coming up with action plans which include; disability benefit to reduce poverty, updating eligibility and improving access to the disability tax credit, helping persons with Down syndrome find and keep good jobs, helping people with Down syndrome advance in their careers or become entrepreneurs and giving support to employers as they develop inclusive workplaces, embedding disability inclusion labour market programs, creating a new equitable access to reading program to improve access to alternate format reading materials for persons with DS and implementing of the accessibility strategy for the Public Service ensure employment of people with Down syndrome in public services. This would help to promote economic inclusion of people with Down syndrome in Uganda.

²⁸¹Namasaba (n 140).

²⁸² Sullivan (n 41) 2-3.

²⁸³ Ibid.

²⁸⁴ Gelaro (n 36)84.

Uganda should also adopt Kenya's approach in promoting social inclusion of people with disabilities. In doing so the government should develop and launch the Disability Awareness Creation Booklet to guide partners and other actors in raising awareness on disability, to foster respect for the inherent dignity for persons with disabilities and ensure that they live independently and are included in the community.

Ugandan government should also develop the Disability Mainstreaming Strategy to ensure mainstreaming of all their policies, legislation and programs, it should also establish Community-Based Rehabilitation (CBR) sub committees at sub-county level to create awareness on disability issues and to promote inherent respect of human rights and inclusion of Persons with Disabilities in society and it should also sensitize private sector organizations to become more disability inclusive and also organize national-level workshops with people with Down Syndrome, their representatives, development partners, governments to train them on how to promote inclusion. This would help in promoting social inclusion of people with Down syndrome in Uganda and people with disabilities as a whole.

4.6 Conclusion

Both Canada and Kenya are state parties to the CRPD, while Kenya has domesticated the CRDP, Canada has not enacted any CRDP implementing legislation, this was demonstrated in its inclusion policies which were stipulated under the laws which were enacted prior to the adoption of the CRPD. Nevertheless, Canada has come up with a post CRPD action plan which Uganda can use as guide in coming up with its economic inclusion action plan. On the other hand, Kenya's social inclusion policies can be used by Uganda as guide in drafting its social inclusion policies. It should however be noted that Kenya, Canada and Uganda still have a lot to do to ensure health inclusion of people with Down syndrome.

CHAPTER FIVE

5.0 Presentation of Results

5.1 Introduction

This chapter contains a presentation of the data that was collected from 15 respondents using structured interview guides. These results were presented in line with the objectives as follows; to discuss the barriers to inclusion of people with Down syndrome in Uganda, to discuss the challenges which caregivers of people with Down syndrome are facing in Uganda, to suggest possible ways in which inclusion of people with Down syndrome can be promoted in Uganda.

5.2 Response Rate

The sample size of the study were 20 respondents at the beginning of the study; however, the team was able to reach only 15 respondents. As such, the response rate was 75%. This was due to very busy schedules of respondents in NGO's government institutions. Nevertheless, this response rate was adequately representative of the target population thus allowing generalization of data.

5.3 Respondents Categories

The results in table 1 below shows the distribution of the respondents by category.

Table 1: Distribution of respondents by category.

Categories	Count	Valid Percent
Government agencies	2	13.33%
Individuals	9	60%
Homes	2	13.33%
NGO's	2	13.33%
Total	15	100%

In reference to table 1 the respondents from the government institutions comprised of 13.33 % and 60 % individuals, homes constituted 13.33 % and NGO's 13.33 %. This shows that several stakeholders were involved.

5.4 Findings and presentation of Data

5.4 .1 Barriers to inclusion and resilience of People with Down syndrome

Except for the first barrier which was a cross cutting issue, the other barriers were discussed under the different forms of inclusion of people with Down syndrome namely; economic, social, health and education inclusion.

5.4.1.1 Lack of data on prevalence of Down syndrome in Uganda

It was found that at the time of research, the ministry of health had no nationwide statistics on the number of people living with Down syndrome since the last census was conducted in 2014 and most parents of children with Down syndrome had not registered them for fear of shame and stigmatization.²⁸⁵

5.4.1.2 Economic inclusion of people with Down syndrome

It was revealed that due to discrimination and stigmatization at school, unfavorable curriculum and lack of funds to pay school fees most children with Down syndrome dropped out of school as such, they failed to acquire the necessary skills that would enable them to work in the formal sector. That though some of them have acquired vocational skills, they are still dependent on parents due to lack of startup capital. Further, it was noted the government of Uganda has never extended any help to enable people with Down syndrome to get employed.

5.4.1.3 Education inclusion of people with Down syndrome

It was established that in Uganda, most children with Down syndrome attend regular public schools. However, these children experience discrimination and stigmatization since most normal

children do not like associating with them both in class and outside. Janet a mother of a girl living with Down syndrome stated that when she took her daughter with Down syndrome to a regular school, she was badly beaten by her fellow pupils because of her appearance and the child's eyes were operated and as a result she stopped going to school for fear of being beaten.

On the other hand, Christine a mother of a girl living with Down syndrome informed the team that she sent her child to 4 four different schools but the head masters kept on sending her home basing on the fact that normal children do not want to associate with children with Down syndrome, as such, she had to stop taking her to school.

It was also found that other children with Down syndrome who do not attend regular schools go to schools for children with special needs which are very few and very expensive with limited resources to provide all the necessary services for children with Down syndrome. A respondent from Kireka School of Children with Special Needs noted that due to limited funding the school is currently understaffed with a ratio of 1:4. According to the respondent, this has affected learning of people with Down syndrome since they require a lot of attention.

5.4.1.4 Health Inclusion of people with Down syndrome

It was established that the Ugandan health system treats people with Down syndrome as people without disability and that though people with Down syndrome are vulnerable to several diseases and conditions, there are no specific health services which are given to them to enhance their ability to survive. As such, it's upon the parents to shoulder the medical expenses which are often unaffordable by most of the parents who are poverty stricken.

The Country Director of Uganda Down Syndrome Association informed the team that most of the children with Down syndrome have holes in their hearts which need heart surgeries that cost an approximate of 20 million Ugandan shillings at Mulago Hospital. According to him, the surgery is very expensive for most of the parents of children with Down syndrome. He further stated that, though he has tried to lobby for subsidization of the surgeries cost by the government, the government has neglected his plea. He concluded that at the time of conducting the study the association had 7 children in need of heart surgeries and were at the verge of dying if not treated within time.

It was also found that most of the medical workers in Uganda lack the necessary skills to diagnose people with Down syndrome and that there is no machines for screening or diagnosing children with Down syndrome, therefore, doctors depend on the physical features of children to determine whether the children have Down syndrome or not . That late identification of Down syndrome in children has made most of them miss early intervention programmes which are vital in their physical and mental development.

5.4.1.5 Social Inclusion of people with Down syndrome

The study revealed that people with Down syndrome experience a lot of discrimination in public places and communities due to lack of awareness and cultural beliefs.

Out of the nine parents who were interviewed, six reported that they and their children have ever been discriminated in places like hospitals, family and schools.

Immaculate a mother of a boy with Down syndrome noted that when the father of her child found out that the child had Down syndrome, he rejected her and told her to go back to her relatives who also chased her from home while telling her that the child is misfortune.

She also stated that when she took her son to a health center in Palisa, the nurses refused to treat him and they told her that she was wasting time and money on her son and that he would die before turning 10 years. She stated that this traumatized her to an extent that she also considered abandoning the child.

Samali a mother of a boy living with Down syndrome stated that the people in her community refer to him as a curse, a ‘zonto’ which is a derogatory term for a mad person. consequently, she hides her son indoors to avoid insults.²⁸⁶

From the above incidents, it can be construed that there is lack of awareness about people with Down syndrome in Uganda as such, people with Down syndrome have not yet been included in the community.

5.4.2 Challenges which care givers of people living with Down syndrome are facing in Uganda

Some of the challenges that care givers of people with Down syndrome are facing like discrimination were ably discussed under the section on the barriers to inclusion of people with Down syndrome, as such, this section focused only on the challenges which were not ably discussed earlier.

5.4.2.1 Lack of food

It was established that children with Down syndrome have high appetite as such, they eat more than normal children. Immaculate a mother to a child with Down syndrome stated that her 3-year-old son takes 3 cups of porridge every day, ²⁸⁷on the other hand, the Executive Director the Noah's Ark (Advocates for Children with Disability) stated she has a child with Down syndrome who takes more 6 cups porridge every day. The respondents concluded that high appetite coupled with lack of funds has made it hard for them to feed these children.

5.4.2 .2 Poverty

The study found that upon giving birth to children with Down syndrome, parents of these children stop engaging in income generating activities since the children need a lot of care and attention. This has led to poverty among the care givers. Out of the 9 caregivers who participated in the study, 5 informed the team that they stopped engaging in income generating activities when they gave birth to children with Down syndrome. Immaculate a mother of a child with Down syndrome stated that she lost her job when she gave birth to a child with Down syndrome because she had to take care of the child and that when she got a house-helper, the said house-helper left because the child was very stubborn and that though recently she got a teaching job, the head master of the school told her that he would fire her if she takes the child to her work place.

5.4.2.3 Lack of funds

The study also found out that both homes and care-givers of children with Down syndrome are facing challenges with funding for feeding, medical treatment and education of children with Down syndrome. They stated that feeding, treating and educating children with DS needs a lot of funds which are often unavailable to the parents and the homes which give care to children with Down syndrome. It was found that lack of funding among parents is caused by the nature of the DS which causes parents to stop engaging in income generating activities to become full time care-givers. On other hand, lack of funding among homes that give care of children with DS was reported to come as a result of lack of donor interest in funding the sector and lack of government intervention. Florence a mother of a girl with Down syndrome stated that her daughter is currently in need of a heart surgery which cost 20 million Ugandan Shillings at Mulago Hospital which she cannot afford since she does not have any income generating job. On the other hand, the Executive Director of Noah's Ark (Advocates for Children with Disability) stated that the government policies on registration of NGOs is bureaucratic which has made it hard for charity organizations to register and qualify for grants which would have helped in funding better services for children with Down Syndrome.

5.4.2.4 Lack of free and specialized education for people with Down syndrome

The study found that there is no specialized education for people living with Down syndrome in Uganda, as such, children with Down syndrome study from normal schools with normal syllabus which does not cater for children with Down syndrome. Parents of children with Down syndrome stated that due to the unfavorable learning conditions, most of the children drop out of normal schools. On the other hand, the parents who took their children to schools of children with special needs informed the team that it is very costly to educate these children as they are often required to pay more than the case would be for normal children.

5.4.3 Possible ways in which inclusion of people with Down syndrome can be promoted in Uganda.

5.4.3.1 Awareness creation

The study established that all the respondents were of the view that awareness needs to be created to promote inclusion of people with Down syndrome. That awareness should be created mainly in the communities, schools and hospitals to inform them about people with Down syndrome and to fight discrimination and stigmatization.

5.4.3.2 Building of a Center for people with Down syndrome

All the respondents suggested that a center should be built for people with Down syndrome in Uganda. The Country Director of Uganda Down Syndrome Association stated that this center should have a medical section which provides all kinds of medical services to people with Down syndrome, have a school section which renders specialized education to people with Down syndrome and residence sections where children with Down syndrome can reside. According to him, putting up a center for people with Down syndrome will ensure early intervention through physiotherapy, safety, close monitoring and prompt treatment of people with Down syndrome and also reduce discrimination and stigmatization of children with Down syndrome in schools and hospital.

Immaculate a mother of a child with Down syndrome stated that putting up a center will help her in taking care of the child and give her time to go and work and get some money to take care of herself and her son.

On the other hand, Florence a mother of child with DS stated it will reduce on the cost of treating her child and feeding since the father of the child only provides her with what to eat and the rest are left to her.

5.4.3.3 Lobbying for subsidization of the cost of heart surgeries

The parents of the children with DS also recommended the NGOs should lobby the government to subsidize the cost of heart surgeries which must be done on children DS with holes in their hearts from Mulago Hospital.

5.4.3.4 Training people with Down syndrome with vocational skills and providing them with startup capital.

It was established that people with Down syndrome have learning disabilities per se they are unable to cope up with normal education curriculum and syllabus, however, they have the ability to learn vocational skills like knitting, beading, carpentry and making doormats amongst others. Most of the respondent recommended that the government and the NGOs should provide vocational trainings, other life skills and start capital to people living with Down syndrome so as to help them get income which they can use to sustain themselves.

5.5 Discussions of results

There is no doubt that people with Down syndrome are prone to mental health problems as well as their caregivers. The study found that people with Down syndrome in Uganda are excluded from education, employment, health care and communities. It was also found that the most prevalent cause of exclusion is discrimination and stigmatization from schools, communities and hospitals. While two respondents stated that due to discrimination and stigmatization at school, their children stopped attending school, two respondents noted discrimination and stigmatization in the community forced them to keep their children in doors for fear of insults.

According to Ashimwe, mental health issues among people with disabilities are associated with emotional climate at home and at school where most persons with disabilities are predominantly victims of attitudinal biases.²⁸⁸ On the other hand, Down syndrome Australia notes that people with Down syndrome experience mental illness due to social and health barriers rather than the disability itself. It further notes that those social barriers include; poor community inclusion, bullying, low expectations, limited access to meaningful work and social activities, while health barriers include; lack of appropriate doctors or therapists among others.²⁸⁹ In relation to the above argument, exclusion of people with Down syndrome in schools and communities through discrimination has made them vulnerable to stress, depression, anxiety and other mental health issues.

²⁸⁸ Ashimwe (n 53).

²⁸⁹ Down syndrome Australia (n 54).

Moreover, it should be noted that raising and caring for a child or an adult with DS is an additional effort for the caregiver and the family in general because individuals with DS continue living with their parents also into adulthood. It is widely acknowledged that family caregivers are more vulnerable to psychological distress with higher rates of depression and anxiety.²⁹⁰ Several studies have found that caregiving of children with DS has an impact on parenting stress,²⁹¹ emotional distress, depression and anxiety because they assume full responsibilities of providing physical, emotional, drug assistance to the people with Down syndrome.²⁹² It is well known that people with DS need special permanent care that extends throughout their entire lives, however, most of parents when left alone to shoulder the varying demands they become stressed, depressed and anxious.²⁹³ The current study found that people with Down syndrome in Uganda are excluded from education, employment, health care and the communities. This means the caregivers of people with Down syndrome in Uganda have to cater for all their special needs which are quite demanding financially yet all the respondents noted that they have no funds to cater for the needs of these people. It is therefore relevant for the government to take appropriate measures to ensure inclusion of people with Down syndrome in education, health, employment and communities to avert the mental health related effects on both the people with Down syndrome and their caregivers.

5.6 Conclusion

From the above findings it's clear that people with Down syndrome in Uganda are excluded from education, employment, health care and the communities, thus, they are vulnerable to depression, anxiety and other mental health issues and the government should work in collaboration with NGOs, the local government and communities to ensure proper implementation of laws and putting in place Down syndrome inclusive policies to promote inclusion of people with Down

²⁹⁰ Alina Chiracu, Germina-Alina Cosma, Amalia Raluca Stepan, Marian Alexandru Cosma, Ionuț Corlaci, Eleonora Daniela Ciupeanu Călugăru, Florin Voinea, Mihaela Zăvăleanu, Horia Alin Burileanu and Taina Avramescu, 'Psychological Capital, Quality of Life, and Well-Being in Mother Caregivers of Individuals with Down Syndrome' (2023) 14 FP 2.

²⁹¹Dias (n 55).

²⁹² François Poumeaud, Clotilde Mircher, Peter J. Smith, Pierre-Antoine Faye and Franck G. Sturtz, 'Deciphering the Links between Psychological Stress, Depression, and Neurocognitive Decline in Patients with Down Syndrome' (2021) 14 Neurobiology of Stress 2.

²⁹³ Ibid.



syndrome in Uganda which in the end will not only promote the mental health of people with Down syndrome but also the mental health of their care givers.

CHAPTER SIX

6.0 Conclusions and Recommendations

6.1 Introduction

The study set out to analyze the state of mental health in Uganda a case study of inclusion of people with Down syndrome. i.e. to examine laws which provide for inclusion of people with Down syndrome, to discuss barriers to inclusion of people with Down syndrome in Uganda, to discuss the challenges which caregivers of people living with Down syndrome are facing in Uganda, to analyze the best practices which were adopted by other jurisdictions in promoting inclusion of people with Down syndrome and to suggest possible ways in which inclusion of people with Down syndrome can be promoted in Uganda. This chapter presented conclusions and recommendations with respect to the objectives of the study.

6.2 Conclusions

In conclusion, much as the Constitution of Uganda and the Persons with Disabilities Act 2020 provide for inclusion of people with Down syndrome, the available inclusion policies do not specifically cater for the specific needs of the people with Down syndrome which are relevant in their inclusion. Further, the current laws have no regulations to guide their implementation as such, people with Down syndrome in Uganda are excluded from education, employment, health care and the communities due to lack of awareness, lack of specialized medical treatment, education and funding. This has made not only them but also their caregivers vulnerable to stress, depression, anxiety and other mental health issues. Consequently, Uganda as a country has a lot to do and learn from other jurisdiction to promote inclusion of people with Down syndrome.

6.3 Recommendations

In relation to the findings, the recommendations are as follows;

6.3.1 To the Government

The government of Uganda should carry out a disability census to come up with data on prevalence of Down syndrome in Uganda. This will not only ensure proper planning and budgeting for people with Down syndrome in Uganda but also enable the government to come up with policies which are Down syndrome inclusive.

The government of Uganda through the Ministry of Education, the Ministry of Health, the Ministry of Gender Labour and Social Development, NGOs and communities should create awareness about Down syndrome by providing families, practitioners and policy makers with updated and accurate facts about Down syndrome, and also by carrying out Down syndrome campaigns and ensuring national celebration of the world Down syndrome day. Those trainings and campaigns should target, schools, health workers and the communities. This will reduce discrimination and stigmatization of people with Down syndrome in public places.

The Government of Uganda should allocate funds for equipment, infrastructure and providing specialized training of teachers to provide specialized education to the children with Down syndrome to ensure inclusive education.

The government should also allocate funds for acquiring equipment and put in place infrastructure for testing, diagnosing and treating people with Down syndrome in addition to providing specialized training for health workers to enable them identify, diagnose and treat people with Down syndrome. This will ensure health inclusion of people with Down syndrome in Uganda.

The government should also make regulations to guide the implementation of the Persons with Disability Act 2020 and develop a stronger monitoring strategy on implementation of its provisions. This will ensure inclusion of people with Down syndrome in Uganda.



The government of Uganda should also consider ratifying the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa of 2018. This will guide Uganda in coming up with policies which promote inclusion of people with Down syndrome.

The government of Uganda should come up with a policy which provide health insurance to cover for people with Down syndrome. This should especially cover major treatments like heart surgeries of children with Down syndrome.

6.3.2 Non-governmental Organizations

Partnership with other NGOs to cover the cost of heart surgeries

The NGOs should partner with other NGOs which carry out heart surgeries to cover up the cost surgeries or provide free surgeries to children with Down syndrome to ensure that the lives of children with Down syndrome are saved.

Building of a Center for people with Down syndrome

The government with the support of NGOs/ donors should build a center for people with Down syndrome. This center should have a medical section well equipped to provide all kinds of medical services including; screening, testing, diagnosing, monitoring and treating of people with Down syndrome. It should also have a well-equipped school section with specialized teachers to educate people with Down syndrome and a syllabus which include early intervention programmes, life skills and vocational training. The center should also have a residential section which takes care of orphans and abandoned people with Down syndrome. This will ensure early intervention through physiotherapy relevant in their development, safety, close monitoring and reduce stigmatization and discrimination of people with Down syndrome in schools, hospitals and the community.

Equipping people with Down syndrome with vocational skills, life skills and talent building.

The government and the non-state-actors should come up with programs that are focused on training people with Down syndrome with vocational skills and life skills like knitting, beading,



carpentry and making doormats and talent building. This will help people with Down syndrome to get income which they can use to sustain themselves.

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