COMMUNITY BASED MENTAL HEALTH CARE: A NECESSITY FOR REALISING THE RIGHT TO INDEPENDENT LIVING AND COMMUNITY INCLUSION OF PERSONS WITH MENTAL DISABILITIES IN UGANDA

By

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DISSERTATION

SUBMITTED IN FULFILMENT OF THE

REQUIREMENTS FOR THE AWARD OF THE

DEGREE OF DOCTOR OF PHILOSOPHY IN LAW

DEPARTMENT OF PRIVATE LAW

FACULTY OF LAW

THE UNIVERSITY OF CAPE TOWN,

SOUTH AFRICA

DECEMBER 2022

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DECLARATION

I, PATRICIA ATIM P'ODONG [Student Reg. No ATMPAT001], do HEREBY declare to the Doctoral Degree Board of University of Cape Town that save for direct quotes from or references to the existing literature which I have duly acknowledged in accordance with the University Regulations, the work presented herein is my own. It has not been submitted in this or any other university or institution for any degree or award.

20th December 2022

Signed:

ACKNOWLEDGEMENT

I am grateful to the distinguished University of Cape Town for having granted me the opportunity to pursue this Doctoral study.

My profound gratitude goes to my supervisor, Professor Amanda Barratt for all her patience with me, encouragement, intellectual input, guidance and understanding.

Sincere appreciation to my colleagues at the School of Law who provided the necessary impetus and provocation for me to undertake the PhD study. Thanks for the continued mentorship in my career. I also value the support I got from SHUREA project in partnership with the Centre for Human Rights, University of Pretoria, and the support from Public Interest Law Clinic (PILAC) colleagues led by Prof. Christopher Mbazira.

It is said that PhD studies is a lonely journey. Luckily, I had a critical team of advisors who have walked this journey with me: Prof Sylvia Tamale, Dr. Patrick Ojok, Mr. Ivan Engoru, Dr. Sadat Mohmeded, Ms. Grancia Mugalula, Ms.Hadija Namyalo and Ms Barbra Lamara. Thank you for all the encouragement and assistance you rendered to me in your different capacities.

To my dearest family, especially my children, you were a significant part of this endeavour and I thank you for understanding when I needed to be alone.

May you all be blessed.

LIST OF ACRONYMS

ACHPR	African Charter on Human and Peoples' Rights
ADP	African Protocol to the African Charter on the Rights of Persons with Disabilities
APDK	Association of Persons with disabilities in Kenya
AYC	African Youth Charter
CAT	Convention Against Torture, Inhuman or Degrading Treatment or Punishment
CBRS	Community-based Rehabilitation Services
CMHCS	Community-based Mental Health Care Services
CBS	Community-based Support Services
CSO	Civil Society Organisation
DPI	Disabled Peoples' International
DPOs	Disability Persons Organisation
EAC	East African Community
ECCL	European Coalition for Community Living
ECT	Eletro-convulsive therapy
ENIL	European Network on Independent Living
EOC	Equal Opportunities Commission
FHRI	Foundation for Human Rights Initiative
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICIDH	International Classification of Impairment, Disability and Handicap
KMHP	Kenya Mental Health Policy

KNHEC	Kenyan National Human Rights and Equality Commission
MDAC	Mental Disability Advocacy Centre
MDAs	Ministries, Departments and Agencies
MGLSD	Ministry of Gender Labour and Social Development
MHA	Mental Health Act No. 15 of 2019
MHCA	Mental Health Care Act No.17 of 2002
MHCUs	Mental Health Care Users
MHU	Mental Health Uganda
MI Principles	UN General Assembly Principles for the Protection of Persons with Mental Illness and Improvement of Mental Health Care
MNS	Mental, Neurological and Substance Use
MTA	Mental Treatment Act 1964
MTO	The Mental Treatment Ordinance N0. 5 of 1938
NAD	Norwegian Association for the Disabled
NCAPPWDs	National Comprehensive Action Plan on the Rights of Persons with Disabilities
NCD	National Council for Disability
NCPWDs	National Council for Person with Disabilities
NDFPWDs	National Development Fund for Persons with Disabilities
NDP	The National Disability Policy
NGOs	Non-Governmental Organisations
NMHPFSP	National Mental Health Policy Framework and Strategic Plan 2013-2020
NODPSP	National Objectives and Directives Principles of State Policy
NPA	National Planning Authority
NSAA	National Social Assistance Authority

NUDIPU	National Union of Disabled Persons of Uganda
PA	Personal Assistant
PEPUDA	Promotion of Equality and Prevention of Unfair Discrimination Act N0.4 of 2000
PHC	Primary Health Care
PIL	Public Interest Litigation
PWD Act	Person with Disabilities Act No. 3 of 2020
PWDs	Person with Disabilities
PWMD	Persons with Mental Disability
SAHRC	South African Human Rights Commission
SASSA	South African Social Security Agency
SDGs	Sustainable Development Goals
SSA	Social Assistance Act
UBOS	Uganda Bureau of Statistics
UDHR	Universal Declaration of Human Rights
UFDS	Uganda Functional Difficulties Survey
UHRC	Uganda Human Rights Commission
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UN ECOSOC	United Nations Economic and Social Council
UPIAS	Union of Physically Impaired Against Segregation
UWEP	Uganda Women Entrepreneurship Programme
VHTs	Village Health Teams
YBU	You Belong Uganda
YLP	Youth Livelihood Programme

DEDICATION

To my colleagues in the disability movement in Uganda, some of whom are living with mental disabilities, and whose life experiences and passionate struggle for disability rights and social transformation provoked my interest in pursuing this study.

To my lovely children, Apiyo Grace, Acen Naomi, Opiyo Jordan, Ocen Joshua and James Austin Odong-Yuyu. Through this process, I have learnt that its true to never give up on your goals.

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As a result of increased knowledge about mental disability and new models of community-based services and support systems, many people with mental disabilities, once relegated to living in closed institutions, have demonstrated that they can live full and meaningful lives in the community, People once thought incapable of making decisions for themselves have shattered stereotypes by showing that they are capable of living independently if provided with appropriate legal protection and supportive services. Moreover, many people once thought permanently or inherently limited by diagnosis of major mental illness have demonstrated that full recovery is possible. Despite these significant advances, however, people with mental disabilities remain one of the most marginalised and vulnerable group in all countries. (Hunt, 'Special Rapporteur Report on everyone to the enjoyment of highest standard of health,' at 381)

REPORTED CASES:

"NOTHING ABOUT US WITHOUT US"[1]

Using the life stories of Kabale, Mwase, Kamuhanda and Mudoola, as published in the media and court records, I attempt to depict the reality of a life of marginalisation, institutionalisation, stigmatisation, human rights violation and social exclusion of persons with mental disabilities (PWMDs) in Uganda.

a) Benon Kabale[2]

Kabale was first diagnosed with bipolar affective disorder in 2005. At that time, he was pursuing a Bachelor's degree at Makerere University. But, because of the limited financial support and the adverse drug effects, he eventually dropped out of the University. During his illness in 2005, he was first admitted to Jinja Referral Hospital, and later transferred to Mulago National Referral Hospital for easier access to psychiatric services. Subsequently, in October 2010, he was admitted to Butabika Hospital where he was subjected to horrifying treatment of seclusion. As he narrated to the court,

> I was subjected to coercive treatment, seclusion in a side room which had no toilet facility. This forced me to urinate and excrete in the same room and then endure sharing the room with such excretes for the whole time I was in seclusion. I was locked up for very unreasonable hours, without any supervision, enduring very cold environment, while stripped naked and left in a dark room with no toilet facility, no access to food and water for over 24 hours.[3]

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[1] Callus and Camilleri-Zahra, ''Nothing About us without Us", at 3 is a slogan developed by the disability movement to advocates for inclusion, involvement and participation of PWDs in all matters regarding them.

[2] Kabale, 'Personal Experience, at 2; *The Centre for Health, Human Rights and Development (CEHURD) and Kabale Benon v The Attorney General,* High Court Civil Suit No. 094 of 2015. The story is extracted from the record of proceedings in this constitutional petition; 'Benon Kabale, 'Testimonial on Mental Health in Uganda'. Available at https://www.youtube.com/watch?v=d7zATIQUx1I. (Accessed on 20th November 2018); Also see, Civil Rights Defenders, *'The Rooms have Strong Mental Doors-Even if You Shout, You cannot be Heard',* 3rd October 2018; Kabale, 'A Critical Overview' at 2.

[3] *Ibid*, at 4.

This experience in Butabika Hospital led Kabale to institute a constitutional petition *CEHURD and Kabale Benon v The Attorney General,* seeking various orders including: a declaration that the medical practice of seclusion and in a filthy room amounted to a violation of the rights to prohibition of cruel, inhumane and degrading treatment; as well as the right to a clean and healthy environment as guaranteed under Articles 24 and 39 respectively of the Constitution of the Republic of Uganda, 1995 (Uganda Constitution, 1995). Although the court did not declare seclusion as unconstitutional medical practice, it nevertheless held that seclusion in an unhygienic environment is indeed a violation of Article 24 and 39 of the Constitution.[4] Kabale is currently a disability rights activist and the Executive Director of Mental Health Recovery Initiative.[5]

b) Perez Mwase[6]

At the time of filing the petition in 2017, Perez was 12 years old and a resident of Buyende District. At 4 years of age, Perez was diagnosed by a Child and Adolescent Psychiatrist with severe form of a neurodevelopment disorder called Autism Spectrum Disorder (ASD). His parents visited various health facilities for treatment of his condition but failed to receive any treatment. Consequently, his parents resorted to maintaining him at home where he was tied to a tree most of the day. None of the primary health facilities within his community provided any form of health care or other services necessary for the detection, diagnosis, rehabilitation and habilitation of Mwase. Due to failure to access appropriate health and disability specific services at an early stage of his life, Mwase suffered irreparable damage. Hence, the petition against Buyende District Local Government and the Attorney General seeking a declaration that failure by the Government to provide disability

[4]*Ibid*, at 24-25.
[5]Kamurungi Elizabeth, 'Mental health activists task Government on restoration of services' *The Daily Monitor*, 17 March 2021.
[6]*Centre for Health Human Rights and Development (CEHURD), Namwebya Lovisa, Esther Naigaga and Perez Mwase (Suing through a next of friend) v Buyende District Local Government and Attorney General of the Republic of Uganda*, Civil Suit No. 135 of 2017.

specific health care services to Mwase is a violation of his fundamental right to health.[7] In the recently passed exparte judgement, court in favour of the petitioners held inter alia, that the failure of the 1st and 2nd defendant to provide early access to early detection services for autism and rehabilitation services to the 4th plaintiff (Perez) at the Primary Health Care level was a violation of his (the 4th plaintiff) rights to health, equality and non-discrimination, human dignity and the realisation of his full potential.

c) Sunday Kamuhanda[8]

At the time Kamuhanda's story was published in the *New Vision* newspaper, he was 50 years old and detained in Katojo prison in Fort Portal, Kabale District. Kamuhanda was arrested for murder in December 1991, and subsequently subjected to medical examination at Butabika National Referral Hospital where he was found to be mentally ill. Following this determination, he was detained awaiting the issuance of Ministerial Orders confirming that he was not in the right state of mind to stand trial in accordance with Section 14 of the Trial on Indictment Act.[9] By 2014, at the time of the publication of Kamuhanda's story, which was 23 years later, the Ministerial Orders had not yet been obtained. During the interview, Kamuhanda expressed his desire to go to his home and be with his child. Kamuhanda is reported to have said,

> I want to go back home. I hope you have come for me. I want to leave. I am tired of this place. I want to see my child.

[7] *Ibid*, at 2. The 2nd petitioner was a mother to Perez and the 3rd petitioner his biological sister and all lead evidence in court relating to their failure to access medical services from various health facilities and the late detection that Perez suffered from Autism.
[8] Mudoola Petride, 'A Mentally ill prisoner's 23 years wait for Justice' *The New Vision*, 12 August 2014.
[9] Trail on Indictment Act Chapter 23, 1971 (Revised 2000).

Since his detention, prison authorities confirmed that Kamuhanda had not been visited by any of his relatives. Unfortunately, Kamuhanda later died before his release from prison.[10]

d) Mark Leslie Mudoola[11]

Mark Mudoola, who was a student and nineteen years of age, died three days after he was admitted to Butabika Hospital on 17th May 2021 to start rehabilitation. He was admitted at the health facility for mental health related condition that had not yet been diagnosed. It is alleged that shortly after his arrival at the hospital, Mudoola was admitted to Kirinya Ward, which he protested saying that he could not share space with 'mad' people. Security guards also demanded that he wears in-patient uniform which he further declined to. It is alleged that Mudoola fought off the security guards when they tried to forcefully undress him and hold him as doctors were trying to administer treatment. It is claimed by Mudoola's family that it is during this scuffle that one of the guards struck Mudoola with a baton on the head that could have caused internal bleeding leading to his death. Currently, this matter is still under police investigation.

My reflections

It is these stories and more that provoked my interest in pursuing this study to advocate for the provision of community based mental health care services (CMHCS) at the Primary Health Care (PHC) level as the pathway to promoting the right to independent living and community inclusion for persons with mental disabilities (PWMDs). There are many other PWMDs in Uganda who share the life

[10]See the list of suspects currently awaiting Ministers Orders in Luzira Upper Prison as provided by Dr. Julius Muron, a Psychiatry doctor at the prison facility, on 11th October 2021. This list was availed to our research team by the said Dr. Muron, during interviews while implementing joint project with Evolve-Foundation for International Legal Assistance (FILA) under the ongoing Project Titled, 'Minister's Orders Access to Justice Project.' The objective of the project is to identify the PWMDs in prison awaiting Minister's Orders and have their cases revived in court and concluded.

[11] URN, 'Police opens fresh inquiries into death of student in rehabilitation at Butabika Hospital', *The Daily Monitor*, 4th July 2021.

experience of isolation, discrimination, family neglect or abandonment, institutionalisation and even death like Kabale, Mwase, Kamuhanda and Mudoola,[12] many of whom have not and will not enjoy the right to independent living and community inclusion as guaranteed in the international and regional human rights treaties discussed below. The government as the primary duty bearer must adopt both legislative and programmatic measures to enable and ensure that such PWMDs have access to appropriate mental health services, are treated with dignity, and enjoy their right to independent living and community inclusion. This thesis will argue that provision of CMHCS as an alternative to institutionalisation of PWMDs in mental health facilities or prisons, is a pertinent and necessary process to realising the right to independent living and community inclusion of PWMDs in Uganda.

[12] MDAC and MHU, 'They don't consider me as a person', at 22. Note: The Mental Disability Advocacy Centre (MDAC) is currently known as Validity. It is still an international non-governmental organization which uses the law to secure equality, inclusion and justice for people with mental disabilities worldwide. See: https://validity.ngo/.

CHAPTER ONE:

> *Mentally disabled persons would like to share the same hopes, dreams and goals and have the same rights to pursue those hopes, dreams and goals like any other human being...mentally ill persons have a right to enjoy a decent life...a right which lies at the heart of the right to human dignity.*[13]

1.1 INTRODUCTION

Institutionalisation refers to a system of confining PWMDs in institutions for extensive periods with living arrangements where those who are confined are unable to exercise their free will and autonomy like non-disabled persons.[14] In many countries, including Uganda, PWMDs are frequently institutionalised in mental health institutions, asylums or prisons in order to provide them with mental health care services or under the pretext of preventing them from being a danger to themselves and to society.[15] These institutions are often large buildings with high walls located in remote areas, but can also be smaller residential facilities or group homes.[16] The UNCRPD Committee recently noted that, institutionalization of persons with disabilities refers to any detention based on disability alone or in conjunction with other grounds such as "care" or "treatment". Disability-specific detention typically occurs in institutions that include, but are not limited to, social care institutions, psychiatric institutions, long-stay hospitals, nursing homes, secure dementia wards, special boarding schools, rehabilitation centres other than community-based centres, half-way homes, group homes, family-type homes for children, sheltered or protected living homes, forensic psychiatric settings, transit homes, albinism hostels, leprosy colonies and other congregated settings. Mental health settings where a person can be deprived of their liberty for purposes such as

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[13] *Purohit & Moore v The Gambia* (2003) AHRLR 96 (ACHPR 2003) Para. 59-60. Communication 241/2001.

[14] United Nations Office of the High Commissioner for Human Rights (UNOHCHR) Report, 'Forgotten Europeans- Forgotten Rights', at 5; UNCRPD Committee General Comment No. 5: Part 11- para 16 (c); WHO, 'Mental Health, Human Rights and Standards of Care', at 4.

[15] WHO, 'Innovations in Deinstitutionalization,' at 16; European Network on Independent Living (ENIL), 'Barriers to Independent Living,' at 23; Ziegler, '*Inclusion for All,*' at 1; MDAC and MHU, 'Psychiatric hospitals,' at 51.

[16] European Expert Group (EEG), 'Common European Guidelines on the Transition', at 10.

observation, care or treatment and/or preventive detention are a form of institutionalization.[17] This practice is historically influenced by the medical model of disability, which perceives a person with disability as one in need of only charity and medical intervention to cure the individual defect.[18] This results in their isolation in institutions. Unfortunately, such institutions are often also associated with poor living conditions and gross violations of the human rights of PWMDs.[19]

To address the problems associated with institutionalisation, recent scholars, human rights bodies and activists have called for a paradigm shift from institutionalisation, to the provision of community-based mental health care services (CMHCS) so as to promote deinstitutionalisation, and the right to independent living and community inclusion of PWMDs.[20] This shift is supported by a number of arguments. For instance, Mansell, Knapp, Brown *et al* contend that the segregation of disabled people in institutions is a human rights violation in and of itself, hence the need for the transition to the provision of CMHCS.[21] CMHCS is more cost-effective than institutionalisation; enables better protection of human rights; improves quality of life of PWMDs who live in the community and reduces community stigma.[22] The World Health Organisation (WHO) argues that community care is about the

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[17] UNCRPD Committee Guidelines on Deinstitutionalisation, including in emergencies: CRPD/C/5 adopted by at its Twenty-Seventh Session held between 15th August and 9th September 2022 and published on 10th October 2022, at para 15.

[18] Kanter, *The Development of Disability Rights,* at 46.

[19] WHO, *World Health Report,* at 49-50; ENIL, 'Barriers to Independent Living,' at 43; Kanter, *The Development of Disability Rights,* at 65-66; Hunt, 'Special Rapporteur Report on everyone to the enjoyment of highest standard of health,' at 380 reports that the Special Rapporteur has received numerous accounts of long term institutionalisation of PWMDs in psychiatric hospitals and other institutions where they have been subjected to human rights abuses including: rape and sexual abuses by other users or staff; forced sterilization, being chained to soiled beds for long period of time, and in some cases, being held inside cages; violence and torture; administration of treatment without informed consent; unmodified use of Electro-convulsive therapy; gross inadequate sanitation; and a lack of food.

[20]WHO, 'Innovations in Deinstitutionalization' at 16-17; ENIL, 'Barriers to Independent Living', at 7-8; MDAC and MHU, 'Psychiatric hospitals,' at 51.

[21]Mansell, Knapp, Beadle-Brown and Beecham, 'Deinstitutionalisation and Community Living', in Ziegler (ed), *Inclusion for All,* at 230.

[22] EEG, 'Common European Guidelines on the Transition', at 50; Mansell, Knapp, Brown *et al* 'Deinstitutionalisation and community living', at 230; MDAC and MHU, 'Psychiatric hospitals,' at 44; WHO, 'Innovations in Deinstitutionalization', at 16; DiGennaro Reed, Strouse, Jenkins *et al*, 'Disabilities and Seniors', at 71.

empowerment people with mental and behavioural disorders, and implies the development of a wide range of services within local settings.[23] In the WHO MIND Project, States are urged to adopt the WHO Pyramid framework arguing that mental hospitals which are least frequented present highest cost, in contrast with self-care, informal community care and CMHCS which has a high frequency of need and can be provided at relatively low cost.[24] The WHO has further advocated that,

> Community care has a better effect than institutional treatment on the outcome and quality of life of individuals with chronic disorders. Shifting patients from mental hospital to care in the community is also cost effective and respects human rights… Large custodial mental hospitals should be replaced by community care facilities, backed by general hospital psychiatric beds and home care support, which meets all the needs of all the ill that were the responsibility of those hospitals. The shift towards community care requires health workers and rehabilitation services to be available at community level, along with provision of crisis support, protected housing and sheltered employment.[25]

The WHO also argues that countries with a strong and sustained political commitment to continuous development of CMHCS that respect human rights and adopt a person-centred recovery approach will vastly improve not only the lives of people with mental health conditions and psychosocial disabilities, but also their families, communities and society as a whole.[26]

CMHCS can also pave way for decongestion and deinstitutionalisation of mental health facilities.[27] Deinstitutionalisation is the process of closure or

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[23]WHO, *World Health Report*, at 50; WHO, 'Guidance on Community mental health services', at 3 notes that the services must be people-centred, holistic and recovery-oriented practice that considers people in their whole lives respecting their will and preferences in treatment; WHO, 'Mental Health Atlas, 2020', at 31; Hunt, 'Special Rapporteur Report on everyone to the enjoyment of highest standard of health,' at 381.

[24] The WHO MIND Project: 'The Pyramid Framework', at 1; WHO, 'Mental Health Atlas 2020', at 70 calls for the need to prioritise investment in primary health care including mental health prevention, promotion, treatment and rehabilitation, to improve efficacy of health management and achieve universal health coverage.

[25] WHO, *World Health Report*, at XII.

[26] WHO, 'Guidance on Community mental health services', at XXII.

[27] Kanter, *The Development of Disability Rights,* at 67; WHO, *World Health Report*, at 50-51.

downsizing of institutions that were originally used for the confinement of PWMDs.[28] The European Network on Independent Living (ENIL) contends that, 'deinstitutionalisation is a means of achieving the goal of independent living and inclusion in the community for all disabled persons regardless of their support needs, gender or age. It involves: the closure of institutions; a moratorium on building new institutions; ensuring access to support in the community and mainstream services; and putting in place measures to prevent institutionalisation in the future.'[29] Kanter notes that the deinstitutionalisation policy has changed the location of treatment from institutions to the community, and that coupled with the increasing cost of institutions, community-based alternatives are preferred.[30]

This paradigm shift led to the inclusion of Article 19 in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD),[31] and on the African continent, Article 14 of the Protocol to the African Charter on the Rights of Persons with Disabilities in Africa (hereinafter referred to as 'ADP').[32] Both treaties require States Parties to protect the right to independent living and community inclusion and reinforce the need for CMHCS to combat institutionalisation of PWMDs. The right to independent living and community inclusion upholds the notion that PWMDs are not left to live highly individualised lives by themselves or in isolation of others, but are provided with the necessary individualised support and barrier free environment so as to enable them exercise their autonomy, free will and preferences in their daily live, and are integrated or included and enabled to

[28]Parker and Luke, 'UNCRPD: A New Right to Independent Living', at 5; Chow and Priebe, 'Understanding psychiatric institutionalization', at 2; EEG, 'Common European Guidelines on the Transition', at 27; Kanter, *The Development of Disability Rights,* at 65.
[29]ENIL, 'Barriers to Independent Living', at 13.
[30]Kanter, *The Development of Disability Rights,* at 67.
[31]The UNCRPD was ratified by Uganda on 28th September 2008.
[32]The ADP was adopted by the African Union at its 30th Summit Meeting held in Addis Ababa from 22 to 29 January 2018. According to the status list, Uganda has to-date neither signed nor ratified the Protocol. Hence, Uganda is not yet bound by it. Notably, a few countries have so far signed the Protocol. Government's attention has also been diverted to the Covid-19 pandemic. However, Uganda will be bound to realise the rights in the ADP once it ratifies it. *See*, status list available on https://au.int/en/treaties/protocol-african-charter-human-and-peoples-rights-rights-persons-disabilities-africa. (Accessed on 12th July 2021)

participate in the communities in which they live just like their non-disabled counterparts.[33]

Suffice to note that at the continental level, the African Commission on Human and Peoples' Rights (hereinafter referred to as the 'African Commission') earlier recognised the need to uphold the human rights and dignity of PWMDs like other human being and repealing laws that perpetuate their long term institutionalisation like the Lunatic Detention Act of Gambia hence violating their right to independent living and community inclusion.[34]

PWMDs in Uganda continue to face gross human rights violations, including: institutionalisation, community exclusion, stigmatisation, discrimination, inhumane and degrading treatment.[35] As Twinomugisha observes:

> PWMD in Uganda are some of the most vulnerable people in society. They are often objects of discrimination, social isolation and exclusion; they are stigmatised and disenfranchised and suffer all kinds of human rights violations. They are subject to violence and abuse. They are confined against their will in institutions such as hospitals and deprived of their freedom, human dignity and other basic human rights.[36]

Murray, Ainslie, Alpough *et al* observe that in Uganda those who are mentally ill are denied access to social services, community activities, development programmes, self-help groups and government welfare.[37] Furthermore, in Uganda, mental health care services are predominantly provided only in mental health

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[33]Article 3 of both the UNCRPD and ADP which underpins the principle of 'full and effective participation and inclusion in society' among others; Also find a detailed discussion of meaning of the right to independent living and community inclusion in Chapter Three.
[34] *Purohit & Moore*, paras 57, 61 and 64.
[35]MDAC and MHU, 'Psychiatric hospitals,' at 22-26; MDAC and MHU, 'They do not consider me as a person', at 22; Ministry of Gender, Labour and Social Development (MGLSD), 'Renewing Commitment', at 13.
[36] Twinomugisha, *Fundamentals of Health,* at 117-118; MDAC and MHU, 'They don't consider me as a person', at 30; Equal Opportunities Commission (EOC) and United Nations Office of the High Commissioner for Human Rights (UNOHCHR), 'The Rights of Persons with disabilities in Uganda', at 6; Lwanga-Ntale, 'Chronic Poverty', at 9.
[37] Murray, Ainslie, Alpough *et al*, 'The Scope', at 878.

facilities in urban areas and there are limited CMHCS at the Primary Health Care Centres closer to the people in the communities.[38] This reality is well illustrated in the introductory case studies of Kabale, Mwase, Kamuhanda and Mudoola. Deduced from the Parliament of the Republic of Uganda Hansards (hereinafter: 'Parliament Hansards'), it is this lacuna that laid the basis for the adoption in the Mental Health Act, 2019 of provisions that now recognise the need for CMHCS, as well as provision of mental health care services even at Primary Health Care Centres to enhance and ensure access to mental health care and treatment at community level.[39] Honourable Bukenya Michael, the then Chairperson of the Sectoral Committee on Health, in justifying the inclusion of provision CMHCS in the objectives of the Mental Health Bill, 2014 (now Mental Health Act, 2019) stated that,

> There is need to offer a holistic approach to the treatment of mental illness…Further that provision of mental health care at primary health centres would give allowance to patients to be admitted in primary health centres which they can easily access.[40]

Further, Honourable Margaret Baba Diri argued that,

> This Bill has come in time. We have been waiting for the amendment of this Bill since 1996 because the old Act of 1964 has been mistreating mentally ill persons. Once you are mentally ill, you are considered a criminal, you are arrested, beaten and thrown in jail for a while before you are taken for treatment…I hope that this Bill will address the issue of treating mentally ill persons humanely by people who know how to handle them rather than being given into the hands of police…There are many people in Butabika who are mentally ill and their relatives do not go to visit them. Even when they get sick or die, their relatives do not care because they do not want to get them back…Regarding treatment, we have only the referral hospitals where the mentally ill can be treated. I think it is important to have these services at health centres III and health centres IV so that if there is any sign of mental

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[38] *Ibid*, at 877; Cappo, Mutamba and Verity, 'Belonging home', at 61.
[39] Section 3(f) and Section 20 of the Mental Health Act, 2019.
[40] Parliament of the Republic of Uganda Hansards, dated Tuesday, 11th September 2018', at 39 and 50. Also see, Parliament of the Republic of Uganda, Sectoral Committee on Health on the Mental Health Bill, 2014 'Report', at 14.

> illness, one can be detected and treated early and only referred to the referral hospitals or Butabika when need arises…[41]

Honourable Safia Nalule, in agreement, submitted that:

> I also wish to emphasize that the users of this Mental Health Bill would like to move away from institutionalisation and go into the community...Therefore, when we get this wide scope of people responsible, I think we are taking the responsibility to the community. As we go on, we would like to get the community knowledgeable about this situation so that they can reduce stigmatisation, discrimination and other kinds of similar treatment.[42]

As a duty bearer, in terms of its treaty obligations and the Uganda Constitution, 1995, government must undertake both legislative and programmatic measures to address the plight of PWMDs in the society.[43] Although the newly enacted Persons with Disabilities Act, 2020 and Mental Health Act, 2019 guarantee fundamental human rights to all persons with disabilities (PWDs) and call for the provision of CMHCS respectively, both instruments unfortunately do not have express stipulations for the protection of the right to independent living and community inclusion for all PWDs. Employing both the social and human rights model of disability, this thesis argues that provision of efficient CMHCS by the government is necessary to address the challenges faced by PWMDs. It further argues that the CMHCS approach will ease access to medical care services; decongest the overcrowded and overburdened national and regional mental health facilities; and pave way for PWMDs to live independently and be integrated and included in their communities.[44] The CMHCS approach will enable PWMDs enjoy their rights on an equal basis with their non-disabled counterparts.

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[41] Parliament Hansards, dated Tuesday, 6th September 2018, at 40.
[42] Parliament Hansards, dated Tuesday 11th September 2018, at 53.
[43] WHO, 'Mental Health Atlas, 2020,' at 37 rightly notes that mental health legislation is a crucial component of good governance and concerns specific legal provisions relating to mental health. Legislations for mental health must comply with obligations under the UNCRPD.
[44] The term 'Integrated' means to bring people or groups with particular characteristics or needs to equal participation in or membership of a social group or institution. Although the UNCRPD and the ADP use 'inclusion', this thesis will use the terms interchangeably since they are both intended to promote participation and inclusion in a given society or activity.

1.2 BACKGROUND

Mental health is not just the absence of mental illness, it is 'a state of (mental) well-being in which every individual is able to realise his/her own potential, can cope with the normal stresses of life, work productively and make a contribution to his or her family and community.'[45] A person's mental health is affected by individual factors and experiences, social interaction, social structure and resources, and cultural values as experienced in everyday life.[46] Despite its significance, mental health continues to be both a public health and human rights concern globally.[47] According to the WHO, mental health conditions contribute to poor health outcomes, premature deaths, human rights violations, and global and national economic loss.[48] Globally, PWMDs continue to face various forms of marginalisation, discrimination, stigmatisation, isolation and exclusion from their communities.[49] They are even overlooked as a target in development programmes.[50] Access to adequate medical care for all PWMDs irrespective of age, economic standing and sex remains a global challenge.[51]

According to the WHO, there are currently over 1 billion 'disabled persons' in the world, 20% of whom live with great functional difficulties in their day-to-day lives.[52] Mental illness affects more than 600 million people globally.[53] It is estimated that 151 million people suffer from depression and 26 million people from schizophrenia. About 125 million people are affected by alcohol use disorder, while

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[45]WHO, *Promoting Mental Health: Concepts, Emerging Evidence, Practice*, at 12. Note that the WHO laudably defines health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'; Galderisi, Heinz, Kastrup *et al*, 'Towards a new Definition of Mental Health', at 231.

[46]*Ibid*, at 13.

[47] WHO, *World Health Report*, at 3; WHO, 'Mental Health Atlas 2020', at 108.

[48] WHO, 'The WHO Special Initiative for Mental Health (2019-2023): Universal Health Coverage for Mental Health', at 1.

[49] WHO, 'Mental Health and Development', at 10; WHO, 'Special Initiative for mental Health', at 2.

[50] *Ibid*', at 2.

[51] WHO, 'Special Initiative for Mental Health', at 2; WHO, *World Health Report*, at 3.

[52] WHO, 'Disabled People in the World in 2021'.

[53] WHO, 'Mental Health and Development', at 2; Hunt, 'Special Rapporteur Report on everyone to the enjoyment of highest standard of health' at 379 reported that mental and behavioural disorder are estimated to account for 12% of the global burden of disease.

40 million people suffer from epilepsy and 24 million people from Alzheimer and dementia.[54] Recent statistics by Ritchie and Roser reveal that nearly 792 million people suffer from a mental disorder globally as presented in the table below.[55]

Disorder	Number of people with the disorder (2017)	Share of males and females with the disorder (2017)
Any mental health disorder	792 million	9.3% male / 11.9 female
Depression	264 million	2.7%male/ 4.1 female
Anxiety Disorder	284 million	2.8% male/ 4.7 female
Bipolar disorder	46 million	0.55% male/0.65 females
Schizophrenia	20 million	0.26 males/ 0.25 female
Alcohol use disorder	107 million	2% males/ 0.8% females

At the national level, Uganda's population is now estimated at 40.3 million, a rise from 34.6 million people reported in the national census report of 2014.[56] The 2019 Uganda Bureau of Statistics (UBOS) report reveals an increase in disability prevalence at 36% of the population of 40.3 million people (that is, 1.4 million people). However, due to the lack of available update data on disability prevalence rates in the country, Uganda still relies heavily on the census report of 2014.[57] According to the Census report, disability prevalence in Uganda was at 12.4% among persons aged 2 years and above.[58] Disability is higher among women compared to their male counterparts.[59] In addition, the disability prevalence is

[54] *Ibid*, at 2.
[55]Hannah and Max, 'Mental Health'. Data deduced from the Institute of Health Metrics and Evaluation; Tolboom, Juanola, Dieleman *et al*, 'Mental Health and Psychosocial,' at 6-7 note that in low-and-middle-income countries mental health conditions account for 11% of the total disease burden.
[56]UBOS Report, 'Bridging the Gap', (2019) at VII; UBOS, 'Census Report 2014', at 22-24. The Washington Group of Questions for Disability Measurement was used to determine prevalence of disability during the Census.
[57]*Ibid*, at 4.
[58]UBOS, 'Census Report 2014', at 22.
[59]*Ibid*, at 22.

higher among those living in the rural areas compared to their urban counterparts.[60] Surprisingly, the census report does not cover the prevalence of the different forms of disabilities. However, the Uganda Functional Difficulties Survey (UFDS) report conducted on a sample of 10,739 households across the country[61] reveals that disability prevalence rates stood at 17% among adults of 18 years and above; 7% of children aged between 5-7 years, and 4% of children between 2-4 years.[62] The survey also reveals variations in age for cases of psychosocial and intellectual disabilities, with adults forming the bulk of cases (9.4%), followed by children between 5-17 years (7.6%), and those between 3-4 years (5.6%).[63] Murray, Ainslie, Alpough *et al* state that 11.5 million people out of a population of 30 million in Uganda suffer from a mental illness.[64] Ojok warns that these estimates should be interpreted with caution as the actual prevalence may vary depending on the methodology and definitions adopted.[65] The statistical variations in the Census and UFDS reports confirm the challenges in accurate data availability as also acknowledged by UBOS[66], and point to the need for Uganda to embark on accurate statistical data collection in

[60] *Ibid*.
[61] Uganda Bureau of Statistics (UBOS), Uganda Functional Difficulties Survey Report (UFDS)', at 10-14. The UFDS 2017 sample was designed to produce reliable baseline indicators at the national and urban-rural residence levels, and for 15 sub-regions. During data collection for the 2016 UDHS, 10,739 households were identified as having a member with a difficulty in one or more of the following areas: vision, hearing, walking, concentration/remembering, concentrating/understanding or self-care. At that time, consent was sought from the household head for another team to visit for the purposes of the UFDS.
[62] *Ibid*, at 16-17.
[63] *Ibid*, at 17.
[64] Murray, Ainslie, Alpough *et al*, 'The Scope', at 877.
[65] Ojok, 'Mapping and Assessment' at 11.
[66] *Ibid,* at 5; WHO-AIMS Report: Mental Health Systems in Uganda', at 11 recognises that there is lack of reliable statistical data in mental health; Uganda in its's Initial Status Report (2010) to the UNCRPD Committee, at para 27 acknowledged the challenge of availability of accurate disaggregated statistical data on persons with disabilities and undertook to address this. Available at http://rodra.co.za/images/countries/uganda/concluding_observations/Uganda%20Initial%20Status%20Report%20to%20the%20UNCRPD.pdf. (Accessed on 22th November 2022). Note that Uganda is currently in the process of preparing its 2nd Status Report to the UNCRPD Committee commissioned by the National Council for Persons with Disabilities and MGLSD. I am a co-consultant in the on-going process of developing the Alternative report commissioned by NUDIPU. Availability of accurate disaggregated data on PWDs and well managed information systems remain a challenge to-date.

accordance with its State obligations under Article 31 of the UNCRPD and 32 of the ADP.[67]

In Uganda, the global challenge of institutionalisation, isolation, discrimination, exclusion and marginalisation of PWMDs prevails.[68] Perceptions of disability as deficiency or curse by the mainstream society serves to devalue the worth and integrity of PWDs as human beings and renders them vulnerable to human rights violation.[69] According to Mugayo, the stigma and discrimination persons with 'mental illness' in Uganda suffer has robbed them of the necessary capabilities required for normal functioning and a dignified life.[70] Influenced by the medical model of disabilities, PWMDs are often institutionalised in mental health facilities for purposes of providing mental health care services.[71] In these mental health facilities, human rights observance often remains wanting as demonstrated by the stories of Kabale, Kamuhanda and Mudoola above.[72] In other cases, PWMDs like Mwase are at times regarded as a bad omen or an embarrassment to the family, and may be restrained with shackles, chains or ropes, or subjected to stoning or expulsion from the community.[73] Traditional beliefs reinforce stigma by viewing PWMDs as demon possession, a curse from the 'gods' and deserving punishment for wrongdoing by exclusion.[74] Such negative perceptions against PWMDs cut across

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[67] Both Articles enjoin States to collect appropriate information and statistical data to enable them to formulate and implement policies.

[68] UBOS, 'UFDS Report,' at 20 considered discrimination as unfair treatment in various aspects of life including: relationships, religious, cultural and social day-to-day activities; MGLSD: Renewed government commitment,' at 13.

[69] WHO, 'AIMS Report: Mental Health systems in Uganda', at 50-51; Nyirinkindi, 'A Critical Analysis,' at 49; Mafabi, 'Disempowering the already Marginalised', at 5; MGLSD, 'Renewing Government Commitment,' at 13; Ojok, 'Mapping and Assessment', at 13.

[70] Mugayo, 'Cultural beliefs', at 1.

[71] Cappo, Mutamba and Varity, 'Belonging home', at 61; MDAC and MHU, 'Psychiatric hospitals', at 22-26.

[72] MDAC and MHU, 'Psychiatric hospitals', at 22-26; MDAC and MHU, 'They don't consider me as a person', at 30-33.

[73] *CEHURD, Perez and Others v Buyende District Local Government & AG*; Byaruhanga, Cantor-Graae, Malinga *et al,* 'Pioneering work in mental health', at 117; Nyirinkindi, 'A Critical Analysis', at 51; Murray, Ainslie, Alpough *et al*, 'The Scope', at 877.

[74] Quinn & Knifon, 'Beliefs, stigma and discrimination', at 555; Orley, 'Culture and Mental Illness', at 20-22; Degonda and Scheidegger, 'Traditional healing in Uganda', at 50-55; Nyirinkindi, 'A Critical

most African societies and lay a fertile ground for the marginalisation, neglect, stigmatisation, isolation and exclusion by families, communities and the State.[75] In addition to the attitudinal and physical abuse that PWMDs face, derogative terminology like *'mulalu'* among the Baganda[76] and *'Lapoya' or 'lababa'* among the Luo[77] (meaning mad) or *'kasiru'* (meaning idiot) are often used to refer to PWMDs, resulting into their disempowerment, disablement and dehumanisation.[78] Such labels place emphasis on the impairment as opposed to the humanness of PWDs.[79] PWMDs also often resort to traditional or spiritual healers who are seemingly more affordable and accessible since they are often located within the communities.[80]

With respect to the state of institutionalisation of PWMDs in Uganda, the Mental Disability Advocacy Centre (MDAC) and Mental Health Uganda (MHU) report that Butabika and Mulago are the two national referral hospitals that admit 4,394 and 165 mental health inpatients respectively annually. In addition, there are thirteen (13) regional referral hospitals with mental health units that admit between 170 and 360 in-patients annually.[81] Although the hospitals in the country can accommodate only 937 in-patients, there is evidently a higher number of PWMDs seeking mental health care services.[82] This results into overcrowding, coercion and poor conditions of care in the health facilities, which causes trauma to the PWMDs

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analysis', at 51; Ojok, 'Mapping and Assessment', at 15-17; MDAC and MHU, 'They don't consider me as a person', at 17-21.

[75] Biegon, 'African human rights system', at 53.

[76] This is the largest ethnic group in Central Uganda belonging to the Bantu.

[77] This is the largest ethnic group in Northern Uganda belonging to the Nilotics.

[78] Mugayo, 'Mental Health in the face of Cultural beliefs', at 11.

[79] Naggitta, 'The Solution is the Problem', at 56.

[80] Abbo, Ekblad, Waako, *et al,* 'The Prevalence and Severity of mental Illness', at 16; Mugayo, 'Cultural beliefs', at 20; Degonda and Scheidegger, 'Traditional healing in Uganda', at 55 also conclude in their findings that well trained traditional healers who work together with allopathic doctors are an important factor in health care systems. Emilio Ovuga J. Boardman and E. Oluka, 'Traditional healers' at 279. MDAC and MHU, 'They don't consider me as a person', at 28-29; Ojok, 'Mapping and Assessment', at 18-20.

[81] MDAC and MHU, 'Psychiatric hospitals', at 12. The regional referral hospitals visited included: Kabale, Mbarara, Arua, Gulu, Soroti, Mbale and Kisiinzi Mission in Rukungiri.

[82] *Ibid,* at 11.

even after getting treatment.[83] Furthermore, prisoners of 'unsound mind' are required to be adjudged by a magistrate upon being presented in court by the officer in charge of prisons, and moved to a mental hospital.[84] Uganda prison authorities reported that there were 30 inmates with mental disabilities in the 224 detention facilities in the country.[85] A case in point is that of Kamuhanda, who remained confined in prison despite his mental illness until his death.[86]

PWMDs face cruel and inhumane treatment even in mental health facilities.[87] The MDAC and MHU report assessed the conditions in Uganda's psychiatric facilities and revealed cases of inhumane and degrading treatment , unhealthy environment and living conditions.[88] These findings resonate with the life experiences of Mudoola — who recently died at Butabika hospital due to the alleged violent actions of the security personnel — and Kabale — who was subjected to seclusion in unhygienic environment, which court found to be a violation of his right to a clean and healthy environment.[89]

Whereas institutionalisation in mental health facilities is the predominant practice,[90] however, due to the limited admission capacity, some PWMDs receive treatment as outpatients from both the national or regional referral hospitals.[91] In

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[83] *Ibid*, at 22-23; Molondynski, Cusack and Nixon, 'Desperate Challenges', at 99; Murray, Ainslie, Alpough *et al*, 'The Scope', at 877-897.

[84] Prisons Act Cap 304, Section 39 (1-4); Sections 3 & 4 gives powers to the Magistrate to adjudge a person found to be of 'unsound mind' and place him/her under the care and treatment of a medical professional in a mental hospital.

[85] Baine Frank, Uganda Prison Service Spokesperson, as interviewed by Mudoola in 'A Mentally Ill Prisoner's 23 Years wait for Justice', *New Vision*, at 48.

[86] See list of some PWMDs currently on remand in Luzira Upper Prison annexed herein.

[87] Uganda Bureau of Statistics (UBOS), 'Uganda Functional Disability Survey Report' (2017), at 27-28; Mugayo, 'Cultural beliefs', at 12.

[88] MDAC and MHU, 'Psychiatric hospitals', at 22-27.

[89] *CEHURD and Kabale v The Attorney General*', at 24; MDAC and MHU, 'They don't consider me as a person', at 30-32; MDAC and MHU, 'Psychiatric hospitals', at 22.

[90] MDAC and MHU, 'Psychiatric hospitals', at 54; Cappo, Mutumba and Verity, 'Belonging home', at 61.

[91] WHO, 'Mental Health Atlas 2020', at 78-79 reports that based on the reported data there were 10.8 mental hospital beds and 71.8 admissions per 100,000 population globally in 2020. Although the median number of mental hospital beds decreased from 12.5 beds per 100,000 populations in 2017 to 10.8 per 100,000 populations in 2020, the median number of admissions increased slightly, from 62.4 to 71.8 per 100,000 population. This could indicate shorter stay in mental hospitals and more effective utilization

other instances, those who are unable to access these facilities like Mwase receive no care at all and continue to languish within their families or in the community.[92] Mugayo notes the lack of adequate psychiatric centres especially in the rural areas, which denies mentally ill individuals of the access of their right to mental health care.[93] There is no information about the average length of time spent in mental health facilities for institutionalised care.[94] Acute cases are admitted until they stabilise. Others are given the relevant treatment and periodically report back to the facility for review and drug re-fills as outpatients.[95] Others are rendered homeless, abandoned by their families and simply remain at the hospital or wonder the streets unattended to.[96] Some like Mwase fail to access treatment and are confined by the family. Even though many people remain untreated, the reports confirm that the practice of institutionalisation of PWMDs premised on the medical model of disability is still the predominant mode of managing PWMDs in Uganda.[97]

The empirical study by Kigozi, Ssebunya and Kizza *et al* revealed several challenges in Uganda's mental health care system.[98] In addition to an over-reliance

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of available beds, and would be in line with Member States' ongoing efforts to gradually shift care towards psychiatric wards in general hospitals and provide community-based facilities to enable rapid reintegration of persons with mental health conditions in society, or it may be as a result of reporting limitations, including the varying definition of types of facilities across countries.

[92] WHO, 'AMIS Report: Mental Health Systems in Uganda', at 13, revealed the number of beds in mental health facilities: 48% in mental hospitals; 37% in community-based psychiatric units (referral hospitals); 15% in other residential facilities and 0% in community residential facilities; MDAC and MHU, 'They don't consider me as a person' at 17-21 reveals the various forms of abuse faced by PWMDs even within the family and community setting.

[93] Mugayo, 'Cultural beliefs', at 12; Molondynski, Cusack and Nixon, 'Desperate Challenges' at 98.

[94] WHO, 'AMIS Report: Mental Health Systems in Uganda,' at 13 recognize that the biggest challenge in determining the number of users per facility and their diagnosis is the lack of information and data; MDAC and MHU, 'Psychiatric hospitals', at 30; Molondynski, Cusack and Nixon, 'Desperate Challenges' at 98. Also see, annexed list of PWMDs confined in Luzira Upper Prison and the length of time spent on remand in prison. Also see, Section 67-70 of the MHA, 2019 on the management of prisoners with mental illness and the issuance of a community treatment order in the even that such persons are discharged from prison.

[95] *Ibid*, at 13; Ojok, 'Mapping and Assessment' at 24.

[96] MDAC and MHU, 'Psychiatric hospitals,' at 46; MDAC and MHU, 'They don't consider me as a person' at 24.

[97] Cappo, Mutamba and Verity, 'Belonging home,' at 61; Twinomugisha, 'A Health and Human Rights Audit', at 15-16; MDAC and MHU, 'Psychiatric hospitals', at 54.

[98] Kigozi, Ssebunya, Kizza *et al*, 'An Overview of Uganda's Mental Health Systems', at 5-9; Murray, Ainslie, Alpough *et al*, 'The Scope', at 877-879.

on institutionalisation, the study identified other challenges and these include: 1) limited human resource since there are only, 0.8 psychiatrists, 0.04 medical doctors, 0.78 nurses, 0.01 psychologists, 0.01 social workers, 0.01 ooccupational therapists and 0.2 psychiatric clinical officers available per patient; 2) Inadequate budgetary support to the mental health sector with only 1% of the health sector budget directed towards mental health, and 55% of these funds allocated to Butabika Hospital, which results in reliance on hospital care and institutionalisation with limited support to Primary Health Centres; 3) lack of beds in community residential facilities; 4) Lack of community-based mental health care and support, and non-compliance with human rights standards.[99]

It is unequivocal that without the requisite CMHCS and support services, PWMDs remain over-institutionalized, or uncared for, or dependent on families who do not have the skills, knowledge or resources to cope with a family member who is mentally ill.[100] Provision of CMHCS and support services is essential to not only enhance access to mental health services but also enable PWMD to live independently and to be included in their community.[101] In Ojok's study, community support for CMHCS advanced a number of benefits including that it: promotes early identification and treatment of mental health conditions; reduces cost associated with going to the hospitals; saves time for caregivers to engage in other tasks; provides an avenue of training and supporting family members; and reduces the need for hospitalisation because not all mental health conditions require hospitalisation and, treatment of some conditions can be continued from home without hospitalisation/admission.[102] In addition, the WHO Mental Health Atlas recently observed that the global reduction in length of stay of PWMDs in mental health facilities may partly be attributed to the changing trends States embarking on

[99] *Ibid*, at 5-9; MDAC and MHU, 'Psychiatric hospitals', at 44-51.
[100] Verity, Turiho, Mutamba *et al*, 'Family care for PWSI', at 2; MDAC and MHU, 'They don't consider me as a person', at 16-18.
[101] Cappo, Mutamba and Verity, 'Belonging home' at 61; MDAC and MHU, 'Psychiatric Hospitals', at 44,54.
[102] Ojok, 'Mapping and Assessing', at 24; ISER, 'Analysis of the Mental Health Bill, 2014', at 6.

the provision of CMHCS.[103] That in the Africa region the length of stay in a mental health facility for less than one year (< 1 year) was at 94%, between one year and five years (1-5 years) stood at 2%, and for less than five years (>5 years) was at 6%.[104]

As discussed in later chapters, Uganda is party to a several international and regional human rights instruments that guarantee fundamental human rights to PWMDs, among which is the UNCRPD.[105] At the domestic level, Uganda has enacted several progressive laws that guarantee the rights of PWDs including: the Uganda Constitution, 1995; the Persons with Disabilities Act 2020; and the Mental Health Act 2019. These rights include the right to live with dignity and be supported to realise their full potential.[106] However, the right to independent living and community inclusion is not expressly stipulated in the PWD Act 2020 or the MHA 2019. Interestingly, section 4 of the PWD Act 2020 only guarantees the right to a home for all PWDs, which is an aspect of the right to independent living. However, despite these progressive legislative gains, the mental health sector in Uganda remains bedevilled by several challenges[107] that inhibit the provision of CMHCS, as well as the realisation of the various fundamental rights guaranteed to PWMDs such as the rights to independent living and community inclusion PWMDs.[108] Molodynski, Cusack and Nixon see the challenges in Uganda's mental health care system as creating an opportunity to adopt a community-based model of service provision which is cost-effective, grounded in communities, minimises the need for

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[103]WHO, 'Mental Health Atlas 2020',79.

[104] *Ibid*', at 80-82. The report further reveals that there is more predominance of male inpatient than female inpatient irrespective of the duration of stay. Further that in low-income countries more than 90% of inpatient service users had a stay of less than one year which may be as a trend for the effective utilization of the limited resources available.

[105] Note that at the time of writing this thesis, Uganda had not yet signed, ratified or acceded to the ADP. See status list at https://au.int/en/treaties/protocol-african-charter-human-and-peoples-rights-rights-persons-disabilities-africa.

[106] *See,* Uganda Constitution 1995: Article 35 guarantees the rights of PWDs, and NODPSP Objective XXVI enjoins the society and the State to recognize the rights of PWDs to respect and human dignity.

[107] WHO, *AMIS Report: Mental Health Care Systems in Uganda*; Kigozi, Ssebunya, Kizza *et al*, 'An Overview of Uganda's mental health care systems'; MDAC and MHU, 'Psychiatric hospitals'; Ojok, 'Mapping and Assessment'; Molondynski, Cusack and Nixon, 'Desperate Challenges'; Mugisha, Halon, Ssebunya *et al*, 'Experience of mental health service users'.

[108] MDAC and MHU, 'Psychiatric hospitals', at 54.

institutional care, and links closely with functional recovery through work and family networks.[109] Mugisha, Ssebunya and Kigozi advocate for improving integration of mental health into primary health care in order to improve access to mental health care services.[110]

This thesis argues that there is a need for a robust, adequately resourced and comprehensive CMHCS system provided at the Primary Health Care level to address the lacuna in the provision of mental health care services in Uganda. A comprehensive CMHCS system will reduce the burden of mental health care on the national and regional mental hospitals, enhance access to mental health services at community level; improve human rights protection, reduce stigmatisation and buttress community inclusion for PWMDs and their families. It will also contribute towards combating over-institutionalisation and promoting the realisation of the right to independent living and community inclusion enshrined under Article 19 of the UNCRPD and Article 14 of the ADP.

Article 19 of the UNCRPD stipulates that:

> State parties to the Convention recognise the equal rights of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:
>
> a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement
> b. Persons with disabilities have access to range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community
> c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

[109]Molondynski, Cusack and Nixon, 'Desperate Challenges', at 99.
[110]Mugisha, Ssebunya and Kigozi, 'Governance of Primary Health Care', at 2.

In the same spirit, the recently adopted ADP provides in Article 14 that:

1) Every person with a disability has the right to live in the community with choices on an equal basis with others.
2) State parties shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of the right to live in the community, on an equal basis with other, including by ensuring that:

a. Persons with disability have opportunity to choose their place of residence and where and with whom they live
b. Persons with disabilities who require intensive support and their families have adequate and appropriate facilities and services, including caregivers and respite services
c. Persons with disabilities have access to a range of in-home, residential and other community support services necessary to support living and inclusion in the community
d. Persons with disabilities have personal mobility with the greatest possible independence
e. Community based rehabilitation services are provided in ways that enhance the participation and inclusion of persons with disabilities in the community
f. Community centres organised or established for persons with disabilities are supported to provide training, peer support, personal assistance services and other services to persons with disabilities; and
g. Community services and facilities for the general population, including health transportation, housing, water, social and educational services, are available on an equal basis to persons with disabilities and are responsive to their needs

Despite these guarantees, the realisation of the right to independent living and community inclusion for PWMDs in Uganda is wanting. The National Union of Disabled Persons of Uganda (NUDIPU) aver that, 'although there are no specific provisions opposing the right to independent living for PWDs in Uganda, there are also no specific legal framework or measures to support independent living for PWDs.'[111] To avert this, the former UN Secretary General, Ban Ki-moon called for the need to step up and address the plight of PWMD. He stated that,

> The rate of 'mental disorder' and the need for care is highest among disadvantaged people- yet these are precisely the group with the lowest access to appropriate services. At the same time, fear of stigma

[111] NUDIPU, 'Alternative Report', at 29.

> leads many to avoid seeking care. The consequences are enormous in terms of disability, human suffering and economic loss. We have a pressing obligation to scale up care and services for mental disorders, especially among the disadvantaged, while stepping up efforts to protect the human rights of those affected.[112]

This thesis relies on both the social and human rights models of disability to make the case for CMHCS as a pathway to realising the rights enshrined in Article 19 of the UNCRPD and 14 of the ADP. It also undertakes a comparative analysis, and draws lessons and best practices from South Africa and Kenya that share similar political, legal, economic and social context with Uganda and have taken some steps in providing CMHCS and promoting the realisation of the right to independent living and community inclusion for their citizenry with mental disabilities.

1.3 STATEMENT OF THE PROBLEM

Marginalisation can be defined as both a process and a condition that prevents individuals or groups from full participation in social, economic and political life.[113] This may be attributed to multidimensional aspects—social, economic and political barriers—all of which contribute to marginalisation of an individual or group of individuals.[114] Social exclusion, on the other hand, refers to the process by which individuals or groups of people are systemically denied access to rights, opportunities and/or services-based on various axes like age, gender, sexual orientation, geography, and disability.[115] PWDs frequently live in deplorable conditions and face physical and social barriers which prevent their integration and full participation in the community, and sometimes lead wretched and marginalised lives.[116]

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[112] WHO, 'Mental Health and Development', at 7.
[113]UK-AID Project, 'Defining Marginalised', at 1.
[114]*Ibid*, at 1.
[115] National Planning Authority, *National Disability-Inclusive Planning Guidelines for Uganda*, at 3.
[116] Robinson, 'Let the World Know' *Report on a Seminar on Human Rights and Disability*, as cited by Hongju Koh: 'Different but Equal', at 7; WHO, 'Mental Health and Development', at 14-15; WHO, 'Mental Health Action Plan 2013-2020' (extended 2030) at 8, para. 13.

The recent paradigm shift from the medical model to the social and human rights model embraced in the UNCRPD and the ADP, is a highly commendable development in the disability rights discourse globally.[117] A key element of this transformation is the recognition that segregation and exclusion of PWDs from their society is not a necessary outcome of physical or intellectual impairment, but the result of conscious policy choices based on false assumptions about the abilities of PWDs.[118] However, despite the celebrated paradigm shift, institutionalisation of PWMDs continues to dominate most health systems globally with limited efforts towards provision of community-based care to facilitate the process of deinstitutionalisation, community inclusion and integration.[119]

The state of marginalisation, stigmatisation and discrimination of PWDs resulting in social exclusion of PWDs in Uganda is glaring.[120] The National Planning Authority (NPA) acknowledges that PWDs face multidimensional exclusions, which cut across more than one domain or dimensions of disadvantage, leading to severe negative consequences for quality of life, wellbeing and future life opportunities.[121] Furthermore, National Union of Disabled Persons Uganda (NUDIPU) also observes that,

> PWDs face various forms of barriers ranging from negative societal attitudes, discrimination, inaccessible physical environment, information and communication technology, to those resulting from insensitive disability friendly regulatory frameworks. These result into unequal access to services in areas of education, employment, health care, transportation, political participation and justice in communities by PWDs.[122]

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[117] Akinbola, 'Paradigm shift', at 304.
[118] Waddington, 'Changing Attitudes', at 33.
[119] Kanter, *The Development of Disability,* at 66; WHO, 'Mental Health Atlas 2020', at 80-81.
[120] MGLSD, 'Renewing Government Commitment', at 13; National Council for Persons with Disabilities (NCD), Disability Status Report, *Uganda* (2019) at 9; UBOS, 'UFDS Report' at 19-20; UBOS, 'Bridging the Gap', at 17; MDAC and MHU, 'They do not consider me as a person', at 18-20.
[121] NPA, 'National Disability-Inclusive Planning Guidelines', at 5; MGLSD, 'National Comprehensive Action Plan (2020-2024)' at 27.
[122] NUDIPU, 'Disability Demands', at 2; MDAC and MHU, 'They do not consider me as a person', at 21-25.

Negative attitudes fuelled by culture and derogatory terminology (embedded even in the laws themselves) exacerbate the situation, thereby culminating in disablement, marginalisation, stigmatization and discrimination.[123] Similarly, the Foundation for Human Rights Initiative (FHRI) attributes the continued marginalisation of PWDs amidst the existence of progressive laws to government's failure to mainstream disability issues in its policy making, budgeting and planning processes.[124]

Specific to mental health care, an empirical study by Sebunya, Kigozi and Ndyanabangi *et al* confirms that the community perceptions towards persons with mental illness are largely stigmatising and discriminative.[125] Contrary to Uganda's legal undertakings, institutionalisation of PWMDs (as influenced by the medical model of disability) in mental health facilities or prisons remains the norm.[126] The Mental Disability Advocacy Centre (MDAC) and Mental Health Uganda (MHU) report reveals that, despite the drive towards deinstitutionalisation and community living enshrined in Article 19 of the UNCRPD, Uganda has no formal or fully established community-based mental health services, rehabilitation programmes, day-care centres or community-based crisis programmes.[127] Yet, community outreach provides a more humane, cost-effective, efficient and less stigmatising approach to providing mental health care.[128] MDAC and MHU further observe that, the lack of mental health services in the community represents a failure by the

[123] Naggita, 'The State and the Law', at 88; Quinn and Knifton, 'Beliefs, Stigma and Discrimination', at 555-557; Abimanyi-Ochom and Mannan, 'Progress and Challenges', at 5; Katsui and Kumpuvuori, 'Human Rights,' at 233; Murray, Ainslie, Alpough *et al*, 'The Scope', at 877.
[124] Foundation for Human Rights Initiative (FHRI), 'Disability in not Inability: Report' at 62; Lang and Murangira, 'Scoping Study', at 17.
[125] Ssebunya, Nsereko, Ndyanabangi *et al*., 'Stakeholder's Perceptions for helping-seeking', at 6-7; Kigozi, Ssebunya, Kizza, Green *et al*, 'Situation Analysis,' at 50-54; MDAC and MHU, 'They do not consider me a person,' 21-25; Murray, Ainslie, Alpough *et al*, 'The Scope', at 877.
[126] MDAC and MHU, 'Psychiatric hospitals', at 12; Cappo, Mutamba and Verity, 'Belonging home', at 61; Varity, Turiho, Mutamba *et al*, 'Family care for PWSI,' at 2.
[127] MDAC and MHU, 'Psychiatric hospitals', at 44.
[128] *Ibid*, at 44.

Uganda government to implement the right to independent living and community inclusion for PWMDs as set out in the relevant treaties.[129]

In addition, Ojok's empirical study reveals that there are no mechanisms adopted by government for the provision of individualised or other CBS services to PWMDs in Uganda. Consequently, the majority of PWMDs, if not institutionalised or are homeless on the streets, rely on Disabled Persons Organisations (DPOs), or their families and/or friend for support.[130] Ojok's findings further reveal that counselling, peer-to-peer support services, self-advocacy, trainings and sensitisation, home visits, vocational skills development are loosely provided by mainly DPOs with limited reach to PWMDs and their families due to resource constraints and geographical limitations. Medical practitioners also provide counselling services to PWMDs and their families but mostly only at the time of diagnosis and treatment.[131] In its Concluding Observations on Uganda, the UNCRPD Committee expressed concern about the prevalence of institutionalisation of PWDs and the absence of community support services that provide for inclusion of PWDs in society. The UNCRPD Committee also raised concerns about the marginalisation of persons with intellectual and psychosocial disabilities due to lack of essential services.[132] It then recommended that, Uganda adopts measures towards deinstitutionalisation and realisation of the right to independent living and community inclusion for all PWDs.[133]

Notably, Uganda is not the only country grappling with the task of deinstitutionalisation and realising the rights to independent living and community inclusion for its citizenry with mental disabilities as demonstrated by the UNCRPD

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[129] *Ibid*, at 54.
[130] Ojok, 'Mapping and Assessing', at 27.
[131] *Ibid,* at 24.
[132]UNCRPD Committee, 'Concluding Observations to Uganda', para. 38.
[133] *Ibid*, paras 39-40.

Committee Concluding Observation and Recommendations to the selected countries in the table below.[134]

Country	Concluding Observation by the UNCRPD Committee	UNCRPD Recommendation to the State
Rwanda[135]	-Concerned that there are PWDs living in isolation and segregated from their families and the communities. -Concerned about the inaccessible infrastructure and services making it difficult for PWDs to participate in the activities of daily life independently in particular in the rural report area.	-Referred to UNCRPD General Comment No. 5 (2017) the Committee. - State party adopt a national strategy on living independently and being included in the community and prevent the isolation or segregation of persons with disabilities. - State party enhance the availability, accessibility and inclusiveness of existing public services and develop community-based services for persons with disabilities to ensure that they have the opportunity to choose their place of residence and where and with whom they live, including in rural or remote areas. - State party ensure the availability and accessibility of support services, including personal assistance services for persons with disabilities

[134]UNCRPD Country Specific Concluding Observations. Available at https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5. (Accessed on 20th Nov 2022).

[135] The Committee considered the initial report of Rwanda (CRPD/C/RWA/1) at its 441st and 442nd meetings (see CRPD/C/SR.441 and 442), held on 14 and 15 March 2019 respectively. It adopted the present concluding observations at its 461st meeting, held on 28 March 2019.

South Africa[136]	-Concerned about the lack of a well-defined national strategic and legislative framework on deinstitutionalization and the absence of independent living community support services that provide for the inclusion of persons with disabilities, particularly for persons with psychosocial or intellectual disabilities. -Concerned that the Gauteng tragedy may discourage the continuation of the deinstitutionalization process in the State party.	- Develop and adopt a national strategic and legislative framework on deinstitutionalization of persons with disabilities, including all the necessary independent living community support services. -Ensure that persons with disabilities are effectively included, through their representative organizations, at all stages of the deinstitutionalization process; - Adopt an action plan at the national, regional and local levels to develop community support services in urban and rural areas, including providing personal assistance, grants and support to families of children with disabilities and parents with disabilities, covering support for assistive devices, guides and sign language
Kenya[137]	Concerned about the institutionalization of persons with disabilities and the absence of community support services that provide for inclusion of persons with disability in society.	-Adopt a strategy for the de-institutionalization of persons with disabilities, within a time frame and measurable indicators. This strategy must involve the participation of organizations of persons with disabilities. -Launch a comprehensive strategy, with time frame and human rights based indicators, to

[136] The Committee considered the initial report of South Africa (CRPD/C/ZAF/1 and Corr.1) at its 399th and 400th meetings (see CRPD/C/SR.399 and 400), held on 28 and 29 August 2018. It adopted the present concluding observations at its 413th meeting, held on 7 September 2018.

[137]The Committee considered the initial report of Kenya (CRPD/C/KEN/1) at its 206th and 207th meetings (see CRPD/C/SR.206 and 207), held on 18 and 19 August 2015, respectively, and adopted the following concluding observations at its 222nd meeting, held on 28 August 2015.

		make community-based services available for persons with disabilities. -Take steps to introduce specific budgetary allocations for the promotion of independent living, including cash transfer schemes for personal assistance services.
Ethiopia[138]	Concerned at the absence of community support services that provide for the inclusion of persons with disability in society. It is also concerned at the lack of availability and accessibility of personal assistance services for persons with disabilities.	- State party enhance the availability, accessibility and inclusiveness of existing public services and develop further community-based services for persons with disabilities to ensure that they have the opportunity to choose their place of residence and where and with whom they live, including in rural areas. - State party ensure the availability and accessibility of personal assistance services for persons with disabilities
Canada[139]	The Committee commends the steps taken by different provinces in the State party towards deinstitutionalization, and welcomes in particular the information that Ontario closed its last residential	(a) Adopt national guidelines on, and provide on a continuous basis advice to provincial and territorial jurisdictions towards, the recognition of the right to live independently and be included in

[138] The Committee considered the initial report of Ethiopia (CRPD/C/ETH/1) at its 271st and 272nd meetings (see CRPD/C/SR.271 and 272), held on 16 and 17 August 2016, respectively. It adopted the present concluding observations at its 289th meeting, held on 29 August 2016.
[139] The Committee considered the initial report of Canada (CRPD/C/CAN/1) at its 318th and 319th meetings (see CRPD/C/SR.318 and 319), held on 3 and 4 April 2017. It adopted the present concluding observations at its 328th meeting, held on 10 April 2017.

	institution for persons with "developmental" disabilities in 2009. However, the Committee is concerned that persons with disabilities continue to be placed in institutions in many provinces, such as Alberta, British Columbia, Manitoba, Nova Scotia, Prince Edward Island and Quebec, and in the territories. It is also concerned about the lack of adequate services and support available to persons with disabilities within the over 600 First Nation communities in the State party.	the community as a subjective and enforceable right for persons with disabilities, reaffirming the principle of respect for the individual autonomy of persons with disabilities and their freedom to make choices about where and with whom to live; (b) Adopt a human rights-based approach to disability in all housing plans and policies at all levels. To that end, the State party should increase the availability of affordable and accessible housing units for persons with psychosocial and intellectual disabilities, as well as support services; (c) Ensure that provincial and territorial jurisdictions set up strategies with time frames to close institutions and replace them with a comprehensive system of support for independent living, including home support and personal assistance for persons with disabilities; (d) Ensure that accessibility legislation, plans and programmes include the accessibility of services and facilities with the aim of facilitating the inclusion of persons with disabilities in the community and preventing their isolation and institutionalization; (e)

		Ensure appropriate service provision within First Nation communities (on reserves) to individuals with intellectual and/or psychosocial disabilities.
Mauritius[140]	-Concerned that families, who are often the sole base of support for persons and children with disabilities, especially those with psychosocial and intellectual disabilities, receive limited assistance from the State. -Concerned that children are removed from family settings and placed in residential institutions, where they lack care and psychological support and are sometimes subjected to cruel, inhuman and degrading treatment. -Concerned that private day-care centres where children with disabilities are placed are neither regulated nor monitored by the State and that children with disabilities continue to be placed in "*centres de sauvegarde*" ("*abris des enfants en détresse*")	- The Committee recommends that the State party urgently remove children with disabilities from the "*centres de sauvegarde*" ("*abris des enfants en détresse*") and develop family and community-based alternatives for those deprived of a family environment. -The State party should initiate without delay a transition from private unregulated day-care centres to inclusive early childhood education and education settings and in the interim, regulate and closely monitor these centres. - The State party should adopt urgent measures aimed at the deinstitutionalization of persons with disabilities and should develop mechanisms at the community level to

[140] The Committee considered the initial report of Mauritius (CRPD/C/MUS/1) at its 214th and 215th meetings (CRPD/C/SR.214 and 215) held on 24 and 25 August 2015 respectively, and adopted the following concluding observations at its 225th meeting, held on 1 September 2015.

		promote choices, autonomy and inclusion for persons with disabilities. -The Committee also recommends that the State party develop effective quality support services for parents caring for children with disabilities and for persons with disabilities to live independently in the community, as well as effective protection systems

Suffice to note that the need for State compliance to deinstitutionalisation by various States culminated into the recent adoption of the UNCRPD Guidelines to Deinstitutionalisation, including Uganda.[141]

To achieve the desired transformation in the lives of PWMDs, it is argued here that Uganda needs to embark on a robust process of provision of community-based mental health care to pave way for the decongestion and deinstitutionalisation of mental health facilities and enable PWMDs enjoy the right to independent living and community inclusion. However, provision of CMHCS should be buttressed with provision of other community-based support services (CBS) so as to promote community inclusion of PWMDs in society. In view of this, the National Union of Disabled Persons Uganda (NUDIPU) demands that,

> Uganda should develop and implement a deinstitutionalisation plan as well as to develop community-based services. Develop and provide individual grants to persons with disabilities to support their independent living in the community, which should include: support to cover assistive devices, personal assistance, guides, sign language interpreters, lotions for persons with albinism and other such types of

[141] UNCRPD Committee Guidelines: Para 4-13 on Duty of State Parties to end institutionalisation.

support to enable inclusion and participation in the community on equal basis with others.[142]

1.4 AIMS AND OBJECTIVES OF THE STUDY

The main and broad objective of this study is to advocate for the need for Uganda to embark on the provision of community-based mental health care services at primary health care level in order to facilitate decongestion, deinstitutionalisation of mental facilities, enhance access to mental health care services and also promote the realisation of the right to independent living and community inclusion for PWMDs in compliance with Article 19 of the UNCRPD and 14 of the ADP.

The specific objectives of the study are:

a) To explore the origin of the practice of institutionalisation of PWMDs globally and determine its application in Uganda
b) To explore the concept of the right to independent living and community inclusion, and its connection to the provision of CMHCS
c) To determine the progress Uganda has made towards promoting CMHCS and the realisation of the right to independent living and community inclusion as enshrined in Article 19 of the UNCRPD and 14 of the ADP.
d) To examine the legal and policy framework on mental health care in Uganda and establish the extent to which they provide for CMHCS and guarantee the right to independent living and community inclusion for PWMDs.
e) To examine examples of best practices from South Africa and Kenya on the strategies for provision of CMHCS and the realization of the right to independent living and community inclusion as possible models for Uganda.
f) To make relevant recommendations and conclusions drawing from the lessons learnt.

[142]NUDIPU, 'Alternative Report', at 29.

1.5 RESEARCH QUESTIONS

a) What is the origin of the practice of institutionalisation of PWMDs and how did it evolve in Uganda?
b) What is meant by the right to independent living and community inclusion, and its nexus to the provision of CMHCS?
c) What progress has Uganda made towards promoting CMHCS and the realisation of the right to independent living and community inclusion as enshrined in Article 19 of the UNCRPD and 14 of the ADP?
d) To what extent does Uganda's legal and policy framework on mental health provide for CMHCS and guarantee the right to independent living and community inclusion?
e) What measures have been adopted by South Africa and Kenya to provide CMHCS and promote the right to independent living and community inclusion?
f) What recommendations and conclusion can be made?

1.6 SIGNIFICANCE OF THE STUDY

The UNCRPD Committee Concluding Observations called on Uganda to address the problem of over-institutionalisation of PWMDs.[143] Under the National Comprehensive Action Plan on the Rights of PWDs, the Uganda government seeks to adopt a strategy for deinstitutionalisation of PWDs and to heed the call by the UNCRPD Committee.[144] Furthermore, the government has also reiterated its commitment towards disability inclusion in all aspects of society and in development.[145] This thesis makes the case for the provision of effective CMHCS systems to address the lacuna in providing mental health care services to PWMDs; to reduce the congestion and overcrowding in mental health hospitals; to combat the practice of over-institutionalisation of PWMDs; and to enable the realisation of the

[143] UNCRPD Committee, 'Concluding Observations to Uganda', para. 39- 40.
[144] MGLSD, 'The National Comprehensive Action Plan 2020-2024', at 15.
[145] MGLSD, 'Renewed Government commitment', at 12; NPA, 'Disability Inclusive Guidelines', at 7.

right to independent living and community inclusion of PWMDs as enshrined in Article 19 of the UNCRPD and 14 of the ADP.

Certainly, the best practices drawn from South Africa and Kenya will also provide useful lessons for Uganda as she strives to achieve her mandate under the UNCRPD and other laws. The recommendation will further inform stakeholder interventions such as: the DPOs, government Ministries, Departments and Agencies (MDAs), academia, disability rights activists, and mental health users on the strategies that can be adopted to promote CMHCS and the realisation of the right to independent living and community inclusion for PWMDs in Uganda.

The focus of this study is the first of its kind in Uganda. Previous studies, as demonstrated in the literature review, largely decried the state of the mental health care sector in Uganda and also advocated for the repeal of the obsolete Mental Treatment Act of 1964 that contained derogatory language and provided no human rights protection to PWMDs.

1.7 SCOPE OF THE STUDY

This is a doctrinal thesis limited to examining law, policies and programmes relating to the mental health care sector, to determine the progress Uganda has made towards promoting CMHCS and the realisation of the right to independent living and community inclusion as enshrined in Article 19 of the UNCRPD and 14 of the ADP.

The geographical and temporal scope is limited to contemporary development in Uganda's laws, jurisprudence and practices from 2006 following the adoption and ratification of the UNCRPD. However, references to relevant historical facts are made to clarify the current status. The study also adopts a comparative approach to draw best practices from South Africa and Kenya in order to propose the best strategies for Uganda to promote CMHCS and realise the right to independent living and community inclusion.

1.8 THEORETICAL FRAMEWORK

This thesis is anchored in the social and human rights model of disability, which advocate for the removal of social barriers and recognition of PWMDs as rights holders. The thesis argues that provision of CMHCS and fulfilment of the right to independent living and community inclusion require the removal of societal barriers and recognition of PWMDs as rights holders. These two complementary paradigms are adopted by both the UNCRPD and ADP.

Historically, a PWD was viewed as an object of charity, then later a subject with impairment and in need of medical intervention. Subsequently, disability became a social issue. Now, with the adoption of the UNCRPD and ADP, disability is viewed as a human rights issue.[146] The medical, social and human rights models continue to manifest and influence the disability discourse to-date. Hence, it is pertinent to delve into a brief overview of the models.

1.8.1 The Charity Model of disability

The Charity model viewed PWDs as objects of charity and welfare who relied on the goodwill of the society, their family members and charitable persons or organisation and had no right to make any demands for better services or facilities.[147] The model reinforced stereotypes of PWDs as helpless and in need of perpetual assistance.[148] Hence, any privileges enjoyed by PWDs in society was premised on charity rather than acknowledgment of PWDs as human beings and bearers of basic rights.[149]

1.8.2 The Medical Model

The Medical model (also referred to as personal tragedy, defect model or individual tragedy theory) advanced the ideology that PWDs suffer from an impairment, disease, defect or deficiency, which requires only medical intervention –

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[146] Akinbola, 'Paradigm shift', at 305.
[147] *Ibid*, at 305.
[148] Nyirinkindi, 'A Critical Analysis', at 53; Wendell, 'Feminist Theory', at 104-124.
[149] Akinbola, 'Paradigm shift', at 306.

which is the responsibility of the person afflicted.[150] Outlining the basic principles of the medical model, Oklin opined that,

> Disability is seen as a medical problem that resides in the individual. It is a defect in or failure of a bodily system and as such is inherently abnormal and pathological. The goals of intervention are cure, amelioration of the physical condition to the greatest extent possible, and rehabilitation.[151]

The model emphasizes that it is up to the individual with a disability to 'overcome' disability through hard work, determination and a positive attitude.[152] The model ignores the effects of the environment on the ability of the PWD to function.[153]

In many countries, the medical model influenced legislation, policies and programmes for a long period.[154] This resulted in over- institutionalisation, exclusion, segregation and separation of PWDs from participating and living in communities with the rest of the society.[155] Wendell has challenged the medical model of disability

> For being limited and perpetuating the notion of the able bodied that is, those who have control of their bodies, are strong, healthy, independent and productive in society. And on the other hand, being disabled as the 'other' (who is weak, failed to manage their bodies, dependant, unproductive to society and can be ignored by the able bodied)…that those who are disabled and yet able to perform certain tasks performed ordinarily by the able bodies are often perceived as 'heroes' or 'differently able' and yet these may be enabled to perform such tasks by their enabling social and technological environment as well as the extent of severity of their disability.[156]

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[150] Retief and Letsosa, 'Models', at 3.
[151] Oklin, 'What psychotherapists should know about disability', at 26, as *cited* by Retief and Letsosa, 'Models', at 3; Akinbola, 'Paradigm shift', at 307.
[152] Schur, Kruse and Blanck, 'Sidelined or Mainstreamed?', at 9.
[153] Akinbola, 'Paradigm shift', at 307.
[154] For instance, Article 1 of the Declaration on the Rights of Disabled Persons defines a disabled person as 'any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and /or social life, as a result of deficiency, either congenital or not, in his or her physical and mental capabilities.'
[155] Waddington, 'Changing Attitudes', at 44; Picking, 'Working in Partnership', at 11.
[156] Wendell 'Feminist Theory', at 104-124.

The medical model no doubt occasioned gross social injustices to PWDs. It perceived them as objects of charity, placed emphasis on the condition of impairment, paid no attention to the environmental constraints, supported institutionalisation for purposes of treatment and safety of society from the purported dangerous and abnormal person, and hindered PWDs from exercising their full capabilities and inclusion in society. Hence, the development of the social model of disability.

1.8.3 The Social Model

The Social model (also referred to as the social oppressive theory of disability) argues that PWDs are capable, but disabled by the social or environmental factors or barriers in society that inhibit them from executing their full potential.[157] Hence, disability is viewed as a social construction. Lawson notes that perceived through the Social model, disability is produced by social structures and processes and is not an inevitable result of individual difference or biology.[158] This model was expounded by activists with disabilities in the 1970s-80s in Britain and the United States of America. It begun with the Union of Physically Impaired Against Segregation (UPIAS), who in 1976 drew the distinction between 'Impairment' and 'disability', arguing that:

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairment, by the way we are unnecessarily isolated and excluded from full participation in society.[159]

The model distinguishes impairment from disability, suggesting that the former refers to the functional limitations within an individual caused by physical, mental or sensory impairment while the latter refers to the loss or limitation of

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[157] Oliver, 'Theories of Health', at 1446-1449; Oliver, 'Defining Impairment', at 39-53; Barnes and Mercer, '*Exploring Disability*', at 30-32.
[158] Lawson and Priestley, 'The Social Model of Disability', at 5.
[159]The Union of Physically Impaired Against Segregation (UPIAS) and the Disability Alliance, 'Fundamental Principles of Disability', *cited* by Lawson and Priestley *ibid*, at 16.

opportunities to take part in the normal life of the community due to the physical and social barriers.[160] Following the distinction drawn by UPIAS, Oliver advocated for the social model theory, which has been of tremendous influence in the disability movement. Oliver asserted that,

> In the broadest sense, the social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment- whether physical, mental or intellectual. The barriers disabled people encounter include: inaccessible education systems, working environment, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities, and the devaluing of disabled people through negative images in the media -films and television, and newspapers.[161]

The social model holds that, disadvantages associated with disability stem primarily from the failure of the social environment to adjust to the needs and aspirations of PWDs, rather than from the inability of the individuals to adapt to society and the environment.[162] As a result of these environmental barriers, PWDs are oppressed, marginalised and discriminated. Hence, the social model aims primarily at deconstructing and countering the individual model of disability (medical model) as well as addressing issues of marginalisation, oppression and discrimination while trying to denounce and remove the disabling barriers produced by hegemonic social and cultural institutions.[163]

Notably, the medical model of disability favoured the dictates of capitalism and the inclusion of those who were able-bodied to work, and the exclusion from society of those who could not work due to their disability. Oliver opined that,

> Under capitalism, disability became individual pathology, hence abnormality, and disabled people became controlled through exclusion

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[160] Disabled People International (DPI), *Proceedings of the First World Conference* (1982) 105, *cited* by Lawson and Priestley *ibid*, at 16.
[161] Oliver, 'The Social Model in Action', at 21; Oliver, *Understanding Disability'*, at 33.
[162] Waddington, 'Changing Attitudes', at 44.
[163] Oliver, *The Politics of Disablement,* at 11, *cited* by Terzi, 'A Philosophical Critique', at 143-144.

> and through medicalising of disability. That the whole ideology of normal originated within the rise of capitalism, with its need for a workforce defined by people's capacity to be usefully trained and productively employed. It is in this process that the construction of 'able-bodied' and 'able-minded' individuals is significant 'with their physical capabilities of operating the new machines and their willingness to submit to the new work discipline imposed by the factory. Consequently, those who could not be included in the category of ability became identified as disabled persons [otherness].[164]

Social oppressions like stigma and discrimination restricted disabled people's lives more than the impairment. Schur, Kruse and Blank contend that using the social model, stigmatized and powerless people can transform the negative identity attached to disability and claim it in a positive way to challenge traditional power relations.[165] Hence, the social model can be applauded for drawing the distinction between impairment and disability and diverting the focus from the individual; and the shift from viewing persons with disability as responsible for the disability and incapable of performing as effectively in society as their non-disabled counterparts.

However, the social model is not void of criticism. Critics contended that the social model does not acknowledge that PWDs suffer from limitations caused by the impairment which may result in pain, deterioration of quality of life, dependency and early death, in addition to disabling structures in the society. That people are disabled by both their bodies and the society.[166] Morris argues that:

> There is a tendency within the social model of disability to deny the experience of our bodies, insisting that our physical differences and restrictions are entirely socially created. While the environmental barriers and social attitudes are a crucial part of our experience of

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[164] *Ibid*, at 144.

[165] Schur, Kruse and Blanck, '*Sidelined or Mainstreamed?* at 10.

[166] Shakespeare, *Disability Rights and Wrong*', at 3, *cited* by Lawson and Priestley, 'The Social Model of Disability', at 19; Shakespeare, 'Critiquing the Social Model', in *Disability Rights and Wrongs,* at 29-33, 67-93; Shakespeare, 'Critiquing the Social Model,' at 67-93; Terzi, 'A Philosophical Critique', at 146-152 also argues that the social model does not take into account technological advancements that require capabilities and the impairment that hinders operation of one's daily life. More specifically, that the social model overlooks the impairment effects, in terms of their restriction of activities or the possible inabilities to perform different functions.

> disability- and do indeed disable us- to suggest that this is all there is to it, is to deny the personal experiences of physical and intellectual restrictions, of illness, of the fear of dying.[167]

In response to the critics, Oliver asserts that the social model is not an attempt to deal with the personal restrictions of impairment but rather to highlight the social barriers of disability as defined earlier by DPI and UPIAS.[168] It is against this backdrop that the social model developed to advocate for the full inclusion of disabled people in society and for their complete acceptance as citizens with equal entitlements, rights and responsibilities.[169] Oliver also concedes that due to the pain and impairment suffered by disabled persons, in addition to the social barriers, the development of social model of impairment to stand alongside a social model of disability appears inevitable.[170]

Owing to the limitations of both the medical and social models, Ngwena rightly acknowledges the limitations caused by both the impairment and the environment to the individual's life experience and calls for a complementary approach. He opines that,

> A social construction of disability provides a meaningful paradigm in which to understand the definition of disability...disability is a fluid and highly contested construct. The medical model with its focus on intrinsic pathology is limited, though not dispensable paradigm for transacting disability. Disability is more than just the sum total of individual pathology and consequent mental and physical limitations. Extrinsic factors are extremely relevant to meaningful interpretation of disability. The social model, with its overt political nuance, provides invaluable insights into the epistemology of disability and the formulation of normative responses that would otherwise be lost to the medical model operating on its own.[171]

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[167]Morris, *Pride against Prejudice: Transforming attitudes to disability*' at 10, *cited* by Degener 'A human Rights Model', at 39.
[168] Oliver, 'Defining Impairment', at 48.
[169] Terzi, 'A Philosophical Critique', at 144.
[170] Oliver, 'Defining Impairment', at 52.
[171] Ngwena, 'Deconstructing', at 116.

The human rights model espoused in the CRPD and now the ADP, is believed to address the limitations of the social and medical models of disability.

1.8.4 The Human Rights Model

Inspired by the social model of disability and the continued advocacy for the rights of PWDs, the UNCRPD—premised upon the human rights model of disability—was adopted.[172] The human rights model reinforces the notion that PWDs can no longer be viewed solely as objects of charity or persons in need of medical repair but should rather be understood as human beings who are entitled to and must with dignity enjoy the inherent fundamental rights and freedoms exercised by their non-disabled counterparts. Where these rights are violated, PWDs can hold duty bearers accountable and seek legal remedies.[173] The human rights model complements and strengthens the social model of disability in various ways, including: emphasizing human dignity; it encompasses both first generation and second rights; recognises that PWDs experience pain and suffering because of their impairment and this must be taken into consideration when developing social justice theories; it offers room for minority and cultural identification; recognises that well formulated policies ensure human rights protection and it offers constructive proposals for improving the life situation of PWDs.[174]

In the past, PWDs were often treated as objects to be protected or pitied and not as subjects with rights. The paradigm shift in the UNCRPD sought to ensure the restoration of human dignity to PWDs.[175] According to Quinn and Degener,

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[172] The UNCRPD was preceded by earlier legal instruments like the Declaration on the Rights of Mentally Retarded Persons (UN General Assembly Resolution No.119, Dec 1971), Declaration on the Rights of Disabled Persons (UN General Resolution 3447, December 1975), United Nations World Programme of Action of 1982, The Vienna Declaration and Programme of Action for Disabled Persons (1993), and the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities of 1993, which notably had no force of law to bind States although they set some benchmarks reinforced by the UNCRPD.

[173] Degener, 'A Human Rights Model', at 34-47; Retief and Letsosa, 'Models', at 5.

[174] *Ibid*, at 34-47.

[175] Quinn and Degener, 'Human Rights and Disability', at 14.

> The human rights model focuses on the inherent dignity of the human being and subsequently, but only if necessary, on the person's medical characteristics. It places the individual centre stage in all decisions affecting him/her and most importantly, locates the main 'problem' outside the person and in society.[176]

The purpose of the treaty is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity.[177] States Parties, including Uganda, have the obligation to recognise, fulfil, respect, promote and protect the fundamental rights enshrined in the UNCRPD and the various international, regional and national laws. The notion that States have the responsibility to respect, protect, promote and fulfil human rights arose in the context that the realisation of civil and political rights as well as social economic cultural rights involves a similar process and that there is no reason to perceive these rights as 'negative' and 'positive' rights respectively.[178]

The 'tripartite typology'[179] framework defines the responsibility to 'respect' human rights as the responsibility of individuals and State institutions not to harm the human rights of others through direct, detrimental action; to 'protect' human rights as the responsibility of a third party (usually the State) to prevent and to react to human rights violations committed by others; to 'fulfil' human rights as the responsibility (usually of the State) to provide each person with access to the objects of their human rights.[180]

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[176] *Ibid*, at 14.
[177] Article 1 of UNCRPD.
[178] Karp, 'The location of international practices', at 969-992; Karp, 'Responsibility to respect.', at 83-108; Oloka-Onyango, *'When Courts Do Politics'*, at 166. The obligation of *recognition* is to acknowledge that the right exists in the first place, by subscribing to international and regional instruments that incorporate it. It would also include local incorporation in the constitutional bill of rights. The obligation to *respect* implies that the State adopts measures of enforcement of the right that has been recognized. *Promotion* places an obligation on the State to publicize the right's existence and official recognition, and the obligation to *protect* is to ensure that rights are not violated.
[179] Hunt, '*Reclaiming Social Rights*', at 31.
[180] Karp, 'Responsibility to Protect', at 3.

The framework is thus premised on the foundation that all human rights, whether civil-political or socio-economic, are associated with a full spectrum of duties, especially for the State.[181] Hence, the requirements for the realisation of the civil and political rights and the economic, social and cultural rights takes into cognizance the different measures needed for their realisation.[182] The UNCRPD comprises both civil and political rights and social and economic rights.[183]

Furthermore, in adhering to these obligations, States Parties are required to submit periodic reports to the relevant human rights body that monitors the extent of implementation of the rights enumerated in the specific instrument. Any violation of these rights must be reported if not by the State Party, then at least by the non-governmental organisations through their alternative or shadow reports.[184] The treaty body having assessed the evidence before it, then makes recommendations in its Concluding Observations to the State for better compliance with the treaty obligations.[185] States that fail to comply with the treaty undertakings in their policies, laws, programmes and actions are held to be in breach or violation of their treaty obligations.[186] Such States can be held accountable before the UNCRPD Committee through the reporting and communication mechanism set out in both the UNCRPD and its Optional Protocol.[187] On the other hand, at the regional level, States Parties to

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[181] Oloka-Onyango, '*When Courts Do Politics*', at 160; *Centre for Health, Human Rights and Development (CEHURD) and 2 others v The Executive Director of Mulago National Referral Hospital and the Attorney General* (HCCS No.212 of 2013) para. 19-29 on State obligation to protect, promote, respect, protect and fulfill fundamental human rights and freedoms.

[182] *Ibid*, at 161; Alston and Quinn, 'The Nature and Scope', at 159.

[183] UNCRPD General Comment No.5, para 7 notes that, Article 19 entails civil and political as well as economic, social and cultural rights and is an example of the interrelation, interdependence and indivisibility of all human rights. The right to live independently and be included in the community can only be realized if all economic, civil, social and cultural rights enshrined in this norm are fulfilled.

[184] Mbazira, 'UN Treaty Bodies', at 18.

[185] Chapman, 'Violation Approach', at 12; Alston and Quinn, 'The Nature and Scope', at 185-187.

[186] *Ibid*, at 13-14.

[187] Article 34 of the UNCRPD which establishes the UNCRPD Committee; Articles 35 and 36 which give the UNCRPD Committee the mandate to receive State reports for consideration. Also see, Optional Protocol to the UNCRPD particularly Article 1, which provides that the State Party to the protocol recognize the competence of the Committee to receive and consider communications from or on behalf of individuals or groups of individuals' subject to its jurisdiction who claim to be victims of a violation by the State Party of the provisions of the Convention.

the ADP can also be held accountable following the mechanism before the African Commission on Human and Peoples' Rights[188] or the African Court of Human and Peoples' Rights where a State Party has made a declaration recognising the jurisdiction of the Court.[189]

At the national level, the Uganda Constitution, 1995 spells out the National Objectives and Directives Principles of State Policy (NODPSP). These NODPSP are binding on the State by virtue of Article 8A(1), which provides that, 'Uganda shall be governed based on principles of national interest and common good enshrined in the national objectives and directive principles of State policy.'[190] Objective XVI provides for respect of the human rights and dignity of PWDs. Furthermore, Article 35 recognises the rights of PWDs and the need to take measures to enable them realise their full potential, which therefore places an unequivocal duty on the State to adopt measures to respect, fulfil, promote and protect rights of all PWDs, including PWMDs. Any breach of this obligation entitles a victim or any person to institute an action for the enforcement of human rights and redress under Article 50 of the Constitution against the State or non-state actors,[191]thus confirming the justiciability of the rights enshrined in the Constitution and obligations that arise under the NODPSP.[192]

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[188] Article 34 of the ADP provides for the jurisdiction of both the African Commission and the African Court on Human and Peoples' Rights in monitoring the implementation of the ADP and dispute settlement. Also see, Article 30 and 45 of the African Charter on Human and Peoples' Rights (1981/1986) on establishment of the African Commission on Human and Peoples' Rights and its mandate, which includes: to ensure protection of human and peoples' rights laid down by the Charter (and its Optional Protocols).

[189] *See*, Protocol to the African Charter on Human and Peoples' Rights on the Establishment of an African Court on Human and Peoples' Rights (1998/2004).

[190] Uganda Constitution, 1995, Article 8A (1).

[191] Article 50 of the Uganda Constitution, 1995 permits an aggrieved person or any person or organisation to institute an action against the State or any person or organisation for the violation of rights enshrined in the Constitution. Also see, the Human Rights (Enforcement) Act 2019 which sets out the procedure for actions brought for the enforcement of human rights.

[192] Oloka-Onyango, *'When Courts Do Politics*', at 161 defined justiciability as a right refers to whether the rights can be enforced in courts and violations redressed; *Centre for Health, Human Rights and Development (CEHURD) and 2 others v The Executive Director of Mulago National Referral Hospital and the Attorney General* (HCCS No.212 of 2013) where the court found the hospital in violation of the plaintiffs right to access information regarding their dead baby and the right to health due to the psychological

In addition, although Uganda is a dualist State,[193] it still commits to uphold its foreign treaty obligations under Objective XXVIII (i)(b) and Article 287 of the Constitution. Moreover, the UNCRPD is also enforceable by virtue of section 3 of the PWD Act, 2020.[194] These provisions create room for the justiciability of the rights stipulated in the UNCRPD. Hence, the fact that the domestic legislations and the Constitution restate the rights that are in the UNCRPD, makes them justiciable in a domestic court.

Despite their diversities, all PWDs must enjoy all inalienable, interdependent and indivisible human rights on an equal basis with others. Failure to provide CMHCS to enhance access to mental health care, coupled with the practice of long-term institutionalisation and exclusion of PWMDs, denies them the right to live dignified independent lives and be included in their communities.

Although the medical model remains relevant due to the effect of the impairment of the life experience of PWMDs, this thesis as earlier noted is however, largely grounded within the social and human rights paradigm of disability. This thesis advocates for the need for government to adopt CMHCS so as to promote access to mental health care services and the realisation of the right to independent living and community inclusion of PWMDs.

1.9 LITERATURE REVIEW

A review of the existing literature enabled my understanding of the disability discourse in Uganda. It then led to the realisation that there is a glaring gap in the literature on the question of provision of CMHCS and its impact in promoting deinstitutionalisation and the realisation of the right to independent living and

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torture they had to endure with the loss of their dead baby's body; Mbazira, 'Enforcement,' at 2 confirming that by virtual of Article 8A, the NODPSP are a crucial elements of constitutional interpretation and are justiciable.

[193] For a treaty to be applicable in Uganda, it must be ratified in accordance with the Ratification Act Cap 204.

[194] Section 3(2) of the PWD Act, 2020 provides that, 'The Government and all persons in Uganda shall respect, uphold and promote the fundamental and other human rights and freedoms of persons with disabilities enshrined in the Constitution and the UNCRPD and its Optional Protocol.'

community inclusion of PWMDs in their societies. Related writings have largely focused on the growth of the disability movement in Uganda, which led to the establishment of the National Union of Disabled Persons of Uganda (NUDIPU). NUDIPU lobbied for several ground-breaking developments, such as:

- the adoption of Article 35 in the 1995 Constitution;[195]
- public consciousness raising around the status of PWDs in Uganda, which has largely been characterised by gross marginalisation, discrimination, exclusion and human rights violations despite progressive legislation;[196]

Other literature reviewed has dealt with,

- assessing the state of psychiatric hospitals and levels of human rights observance;[197]
- undertaking an analysis of the state of mental health care systems in Uganda, characterised by inadequate services, limited and demotivated human resources, underfunding, lack of CMHCS and over institutionalisation;[198]
- understanding the nexus between mental health and poverty;[199]
- evaluation the performance of the community-based rehabilitation programme,[200] and

[195] Ndeezi, *The Disability Movement in Uganda,* at 18.
[196] Naggita, 'The State and the Law'; Nyirinkindi, 'A Critical Analysis'; UBOS, *UFDS report*; MGLSD, 'Renewing Government Commitment'; UBOS, 'Bridging the Gap'; MDAC and MHU, 'They do not consider me as a person'; Mugayo, 'Cultural beliefs'; Naggita, 'The Solution is the Problem'.
[197] MDAC and MHU, 'Psychiatric hospitals'; Cooper, Ssebunya, Kigozi *et al*, 'Uganda's Mental Health Systems through a Human Rights Lense'; Molodynski, Cusack and Nixon, 'Desperate challenges'; Cappo, Mutamba and Verity, 'Belonging Home'; Kisakye-Nsanze, 'Better Approach to mental health'.
[198] Ndyanabangi, Basangwa, Lutakome *et al*, 'Mental health profile'; Nsereko, 'The Evolution'; Kigozi, Ssebunya, Ndyananbagi, Kizza *et al,* 'An Overview of Uganda's mental health care system'; Ssebunya, Kigozi, Ndyanabangi *et al*, 'Stakeholder perceptions'; Murray, Ainslie, Alpough *et al*, 'The Scope'.
[199] Sanyu, 'Development Agenda'; Lwanga-Ntale, 'Chronic Poverty and Disability'; Quinn and Knifton, 'Beliefs, Stigma and Discrimination'.
[200]Abimanyi-Ochom, 'Progress and Challenges of Disability in Uganda'; Norwegian Disabled Peoples' Association, 'Evaluating CBR in Uganda'.

- assessing the role of traditional healers in providing mental health services to PWMDs;[201]
- conducting an appraisal of the MHA, 2019[202]
- advocating for the adoption of mental health policy and plans to improve provision of mental health care in Uganda;[203]
- interrogating governance issues that hinder the process of effectively integrating mental health care in primary health care[204]
- emphasizing the need for funding of the mental health sector and inclusion and involvement of mental health service users in the development, designing, planning of policies and programmes[205]
- Advocating for the decolonization of provision of health services, education systems and training of health professionals, so as to promote community consultations and participation and indigenous ideas in the design and provision of health care services.[206]

Closest to this study, is the general call for the transition to the provision of community-based mental health care services in order to enhance access to mental health treatment,[207] the advocacy for adoption of a community-based mental health care model designed by YouBelong Uganda (YBU)— a non-governmental organisation.[208] Similarly, Verity, Turiho, Cappo *et al* also advocated for the need for CMHCS and adoption of a family oriented model to support families to strengthen or improve their capacity as caregivers of persons with severe mental illnesses in

[201]Abbo *et al*, 'Traditional healing practices'; Ovuga, Boardman and Oluka, 'Traditional healers'; Degonda and Scheidegger, 'Traditional healers in Uganda'; Mugayo, 'Cultural belief', at 12; Ssebunya, Nsereko, Ndyanabangi *et al*., 'Stakeholder's perceptions for helping-seeking behaviour', at 6-9.
[202] Twinomugisha, 'A Health and Human Rights Critique'.
[203] Ssebunya, Kigozi and Ndyanabangi, 'Mental Health Policy', at 1.
[204]Mugisha, Ssebunya and Kigozi, 'Governance of Primary Health Care'.
[205] *Ibid*, at 9; Mugisha, Hanlon, Ssebunya et al, 'Mental health users', at 2.
[206] Mulumba, Ruano, Perehudoff, *et al,* 'Decolonising health governance', at 269.
[207] MDAC and MHU, 'Psychiatric hospitals', at 44; Molodynski, Cusack and Nixon, 'Mental health care in Uganda'; Ojok, 'Mapping and Assessment'; Murray, Ainslie, Alpough *et al*, 'The Scope', at 878.
[208] Cappo, Mutamba and Verity, 'Belonging home'.

Uganda.[209] Ochom's study commended the Community-based Rehabilitation (CBR) programme under the Ministry of Gender, Labour and Social Development (MGLSD), but fell short of tackling the subject of CMHCS and the right to independent living and community inclusion for PWMDs.[210]

With specific focus on mental health and over-institutionalisation, there is substantial and informative literature focusing on inadequate mental health care systems, the right of PWMDs to access mental health services and a general critique of the Mental Treatment Act of 1964 (now repealed). Several scholars contended that:[211]

- the MTA was largely influenced by the medical model of disability and emphasized institutionalisation of PWMDs;
- It contained derogative language by referring to PWMDs as persons of 'unsound mind' who are 'idiots' and 'lunatic'; and it lacked provisions on the human rights for PWMDs;
- provided no safeguards against forced treatment;
- had no established tribunal to receive complaints from patients or their caregivers and receive redress in a timely, accessible and least costly manner and
- provided no human rights protection for PWMDs, among others.

The authors advocated for the promulgation of a new law which conformed to the spirit of the UNCRPD, the Constitution and the PWD Act (then of 2006).

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[209] Verity, Turiho, Mutumba *et al*, 'Family care for PWSI', at 9; Ojok, 'Mapping and Assessment', at 39.
[210] Abimanya-Ochom and Mannan, 'Uganda's Disability Journey'; Norwegian Disabled Peoples' Association, 'Evaluating CBR Programme'.
[211] Nyombi and Mulimira, 'Mental Health Laws Part 1'; Nyombi, Kabandana and Kaddu, 'A Critique of the MTA'; Mulumba, 'Analysis of the MTA'; Twinomugisha, *Fundamentals of Health Law*; Nyanabangi, Basangwa, Lutakome *et al*, *Mental Health Profile*; Kigozi, Ssebunya, Ndyanabangi *et al*, 'An Overview of Uganda's Mental Health Systems'.

Commendably, these collective efforts resulted into the recent enactment of the Persons with Disabilities Act, 2020[212] and the Mental Health Act, 2019,[213] both of which contain more progressive provisions towards the protection and promotion of the rights of PWDs as well as those with mental disabilities respectively. Unfortunately, both legislations have no specific provisions regarding the right to independent living and community inclusions.

In summary, as seen above, the literature reviewed clearly demonstrates the worrying state of mental health care services in Uganda, including the lack of a comprehensive community-based mental health care and community support services, to improve the management of mental health and pave way for deinstitutionalisation and the realisation of the right to independent living and community inclusion of PWMDs, among others. Embracing both the social and human rights models of disability, various authors have advocated for relevant strategies to enhance the protection and realisation of the fundamental rights and freedoms guaranteed to PWDs in the Constitution and other international and regional human rights instruments. Some of the strategies include: combating negative societal perceptions, mainstreaming disability rights in government programmes and policies, improving the provision of mental health services and community-based rehabilitation services to PWMDs at primary health care levels, increasing budgetary allocation to mental health, embarking on community awareness and sensitization on mental health, and including PWMDs in the development agenda to combat poverty and unemployment of PWMDs.

Building on the above writings and advocacy dimensions, this research focuses specifically on the need for Uganda to transition from the practice of institutionalisation of PWMDs, to provision of an effective community-based mental health care (CMHCS) system that promotes the realisation of the right to independent living and community inclusion of PWMDs enshrined in Article 19 of

[212] Gazzatted on the 12th February 2020.
[213] Gazetted on the 19th September 2019.

the UNCRP and 14 of the ADP. I argue that this alternative approach will also enhance access to medical care within the communities by PWMDs, promote deinstitutionalisation and decongestion of mental health facilities, combat community stigmatisation and provide better support to families toiling with the burdens of caregiving. Hence, this thesis is timely and will enrich the existing literature.

1.10 METHODOLOGY

This study will employ two research strategies. First, a doctrinal study that will analyse the legal and policy frameworks that govern mental health care and protection of the rights of PWMDs in Uganda. Second, an additional literature review to gather information from various relevant scholarly journal articles, websites, books, and reports from government and non-government institutions and international bodies.

1.11 DEFINITION OF KEY TERMINOLOGY

This section provides an explanation of the key terminology.

a. Disability

The term 'disability' has been a complex and significant subject of debate in the disability movement for a long time. In 1976, the Union of Physically Impaired Against Segregation (UPIAS) argued that 'it is the society which disables physically impaired people. Disability is something imposed on top of our impairment, by the way we are unnecessarily isolated and excluded from full participation in society.'[214] UPIAS defined disability as,

> The disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have

[214] The Union of Physically Impaired Against Segregation (1976), *cited* in Kirch, *Encyclopedia of Public Health*; Lawson and Priestly, 'The Social Model of Disability', at 4.

> physical impairments, and thus excludes them from participation in the mainstream of social activities.[215]

Subsequently, the distinction proposed by UPIAS was adopted by Disabled Peoples' International (DPI) who then distinguished between impairment and disability and stated that:

> 'impairment' as the 'functional limitation within the individual caused by physical, mental, or sensory impairment' and 'disability' as the loss or limitation of opportunities to take part in the normal life of the community due to physical and social barriers.[216]

Hence the recognition of environmental and social barriers as the cause for disability, in line with the social model of disability.

Earlier definitions of 'impairment and disability' were largely viewed through the medical model. For instance, Article 1 of the Declaration on the Rights of Disabled Persons defines a disabled person as:

> Any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and /or social life, as a result of deficiency, either congenital or not, in his or her physical and mental capabilities.[217]

The WHO, in the International Classification of Impairment, Disability and Handicap (ICIDH-1), also defined disability purely on a medical model as follows:

> Impairment is concerned with abnormalities of body structure and appearance and with organ or system function, resulting from any cause: in principle impairment represents disturbance of the organs: Disability, reflecting the consequence of impairment in terms of

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[215] The Union of Physically Impaired Against Segregation, *ibid*. It is reported that it is from this definition that Mike Oliver in 1983 coined the concept of 'Social model of disability'. He focused on the idea of an individual model (of which medical was a part) versus a social model derived from the distinction made between 'impairment' and 'disability' by UPIAS.

[216] Lawson and Priestly, 'The Social Model of Disability', at 4.

[217] Also see, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993), para 17 noted that persons may be disabled by physical, intellectual and sensory impairment, medical condition or mental illness. Such impairment, condition or illness may be permanent or transitory in nature.

> functional performance and activity by the individual: Disability thus represents disturbance at the level of the person: Handicap is concerned with the disadvantages experienced by the individual as a result of the impairments and disabilities: Handicap reflects interaction with and adaptation to the individual's surrounding.[218]

Barnes and Mercer observed that the ICIDH approach relied primarily on the medical definitions and the use of bio-physiological definitions of 'normality'.[219] Similarly, Oliver criticised the ICIDH for concentrating on the individual and attributing disability to the biological pathology without considering the role of society in the disablement of PWDs.[220] To Shakespeare, the ICIDH was flawed for only offering an exhaustive catalogue of physical differences and behaviour variations.[221]

Following such criticism, a revision was made to embrace the social model of disability. For example, in the International Classifications of Functioning, Disability and Health (also referred to as the ICF or ICIDH-2).[222] The ICIDH-2 defined disability at three levels: Body functions, structure and activity; participation and the environmental factors. Hence, ICIDH-2/ (ICF) defines disability as a limitation in a functional domain that arises from the interaction between a person's intrinsic capacity, and environmental and personal factors.[223] Barnes and Merce observe that:

> The ICIDH-2 adopts a so-called "bio-psychosocial" model, which endeavours to synthesize the medical model and social approaches to disablement. By separating "impairment, activity limitations and participation restrictions", it attempts to establish a framework which identifies those aspects which are properly the subject of medical

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[218] WHO, *International Classification of Impairments, Disabilities and Handicaps: A Manual of classifications relating to the consequences of disease* (1980), at 14; Jones, 'Impairment, Disability and Handicaps', at 377.
[219] Barnes and Mercer, *Exploring Disability*, at 24-25; Naggita, 'The State and the Law', at 50.
[220] Oliver, 'The Politics of Disablement', at 10-11.
[221] Shakespeare, '*What is a Disabled person? In Disability, Divers-Ability and Legal Change,* at 25, *cited* by Naggita, 'The State and the Law', at 50.
[222] WHO, *ICIDH-2, International Classification of Functioning, Disability and Health*, at 1. The overall aim of ICIDH-2 classification is to provide a unified and standard language and framework for the description of health and health related States.
[223] *International Classification of Functioning, Disability and Health (ICF), cited* by the UN ECOSOC, *Global Status Report on Disability*, at 31.

> intervention from other areas where social and environmental factors are the major factor.[224]

These efforts culminated into the understanding that disability is the consequence of the interaction of a person's medical impairment with the social barriers in the environment. Today, the celebrated UNCRPD embraces both the medical and social aspects and defines disability as:

> An evolving concept that results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.[225]

Notably, contemporary understanding of disability focuses on both the medical condition and social or environmental factors experienced by an individual that results in disability and disablement. As the WHO affirms,

> Disability is thus not just a health problem. It is a complex phenomenon reflecting the interaction of features of a person's body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environment and social barriers.[226]

In line with the UNCRPD and ADP, Uganda's PWD Act, 2020 defines disability to mean:

> a substantial functional limitation of a person's daily life activities caused by physical, mental or sensory impairments and environmental barriers, resulting in limited participation in society on an equal basis with others and includes an impairment specified in Schedule 3 of the Act.[227]

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[224] Barnes and Mercer, *Exploring Disability*, *cited* by Naggita, 'The State and the Law', at 51.
[225] UNCRDP Preamble, para (e). Note that the ADP provides no definition for the term 'disability'.
[226] WHO, 'Disabilities' https://www.who.int/topics/disabilities/en/ (Accessed on 16th February 2019); Twinomugisha, *Fundamentals of Health Law*, at 121.
[227] Section 1; The 3rd Schedule provides for categories of disabilities, including: Physical disability caused by cerebral palsy, amputation of limbs, paralysis or deformity; Hearing disability including deafness and hard of hearing disability; Visual disability including blindness and low vision; Deaf and blind disability; Mental disability including psychiatric disability and learning disability; Little people; Albinism; Multiple disabilities.

The Ugandan legislature is commended for embracing both the social and medical model in its definition of disability in conformity with the UNCRPD and the ADP.

b. Persons with disabilities

The UNCRPD defines 'persons with disabilities' as those who have long-term physical, mental, intellectual or sensory impairment which in interaction with the various barriers may hinder their full and effective participation in society on an equal basis with others.[228]

Similarly, but in a much broader perspective and without the emphasis on long-term condition, the ADP states that, 'persons with disabilities includes those who have physical, mental, psycho-social, intellectual, neurological, developmental or other sensory impairments which in interaction with the environment, attitudinal and other barriers hinder the full and effective participation in society on an equal basis with others.'[229]

Other literature may use the term 'persons living with a disability' or 'disabled person'. However, the term 'disabled person' has been criticised for placing the disability before the person, resulting into disablement and disempowerment. As the ICESCR Committee noted, 'the term disabled person might be interpreted to imply that the ability of the individual to function as person has been disabled.'[230]

Uganda's PWD Act 2020 does not provide a definition of persons with disabilities, but rather provides for determination of a person with disability.[231]

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[228] Article 1.
[229] Article 1 of the ADP.
[230] ICESCR Committee, General Comment No.5: Persons with Disabilities; para 4.
[231] Section 2 provides that, 'Whenever a question arises whether a person has a disability or not, or where court so requires, a medical doctor with the relevant expertise or an expert appointed by the Council, shall carry out an examination to confirm the disability'.

This thesis adopts the term 'persons with disabilities' within the broader definition of both the UNCRPD and ADP, which recognises both the impairment suffered by a person and environmental barriers which hinder a person's functionality.

c. Mental Health

Both the UNCRPD and ADP have no express definition of the term 'health' or 'mental health'.[232] However, the WHO defines 'health' as a state of complete physical, mental and social well-being and not just the absence of disease and infirmity.[233] Mental health is understood as,

> a state of mental well-being in which every individual is able to realise his/her own potential, can cope with the normal stresses of life, work productively and make a contribution to his or her family and community.[234]

Notably, the right to health, which includes mental health, is guaranteed under Article 25 of the UNCRPD and Article 17 of the ADP.[235] The WHO notes that mental health and mental illness is determined by multiple and interacting social, psychological and biological factors just as health and illness in general.[236] Keyes argues that mental health is said to consist of three components, namely:

> emotional well-being, psychological well-being and social well-being. Emotional well-being includes happiness, interest in life and satisfaction; Psychological well-being one is good at managing the responsibility of one's daily life, having good relationships with others and being satisfied with one's own life; Social well-being refers to positive functioning and involves having something to contribute to society (social contribution), feel part of the community (social integration), believing that society is becoming a better place for all

[232] UNCRPD, Article 25 and ADP, Article 17.
[233] WHO, 'Promoting Mental Health', at 2; WHO: Preamble of the Constitution.
[234] WHO, 'Promoting Mental Health', at 2; Galderisi, Henz, Kastrup *et al*, 'Towards a New Definition,' at 231.
[235] ICESCR General, Comment No. 5: para 34 also recognises the right to physical and mental health of PWDs.
[236] WHO, 'Promoting Mental health', at 2.

> people (social actualisation) and that the way society works makes sense to them (social coherence).[237]

For a long time, the WHO definition of mental health was seen as progressive as it did not consider mental health as the absence of disease and infirmity alone. However, it has been challenged recently as portraying only the positive aspects of life, which is not a true reflection of human existence.[238] Hence, Galderisi, Henz, Kastrup *et al* propose a new definition of mental health which they argue is more comprehensive and inclusive of the various positive emotions and challenges in human life. They argue that:

> Mental health is a dynamic state of internal equilibrium which enables individuals to use their abilities in harmony with universal values of society, basic cognitive and social skills; ability to recognise, express and modulate one's own emotions, as well as empathize with others; flexibility and ability to cope with adverse life events and functions in social roles; and harmonious relationship between body and mind represent important components of mental health which contribute to varying degrees, to the state of internal equilibrium.[239]

However, their critique is contested because the WHO definition also recognises the ability of mentally healthy persons to cope with the 'stresses' of life. As rightly argued by Twinomugisha, mental health, which is a key component of health, is a broad multifaceted and complex subject. It is influenced by a complex mix of biological, psychological, cultural, social-political and judicial factors. It is more than mere absence of mental illness and is vital to the individuals, families and society.[240]

In concurrence with Keyes and Twinomugisha, Friedli argues that positive mental health includes emotion (affect and feeling), cognitive functions (perception, thinking and reasoning), social functioning

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[237] Keyes, 'Mental Health in Adolescence', at 395-402, *cited* by Galserisi, Henz, Kastrup, *et al*: 'Towards New Definition', at 231.
[238] Galderisi, Henz, Kastrup *et al*, 'Towards a New Definition', at 231.
[239] *Ibid*, at 232.
[240] Twinomugisha, *Fundamentals of Health Law*, at 119-120.

(relationships with others in society), and coherence (sense of meaning and purpose in life).[241] These factors enable one to live a healthy life, build resilience and have capability to adapt to the stresses of daily life.[242] Friedli further asserts that poor mental health is thus both a cause and a consequence of the experience of social, economic and environmental inequalities. Mental health problems are more common in areas of deprivation, and poor mental health is associated with unemployment, less education, low income or material standard of living, in addition to poor physical health and adverse life events.[243]

In agreement with Keyes, Twinomusisha and Friedli, this thesis adopts the most comprehensive understanding that mental health is not only the absence of mental illness, but the general well-being of a person comprising all the emotional, psychological, economic, spiritual, social and cultural factors that enable the individual to cope with the various positive as well as challenging aspects of life and still maintain a good state of both body and mental equilibrium to cope with adversity and reach their full potential, as well as participate and be included in society.

Mental disability, on the other hand, may refer to impairments or conditions that have a long-term effect on a person's mental well-being. When these impairment or conditions are combined with environmental and social factors such as stigma and discrimination, they deny that person the enjoyment of his or her fundamental rights and freedoms enshrined in various legal frameworks.[244]

e) Persons with mental disability

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[241] Friedli, 'Mental Health, Resilience', at 2.
[242] *Ibid,* at 15.
[243] *Ibid*, at 35.
[244] Twinomugisha, *Fundamentals of Health Law*, at 122.

Other literature may use the terminology 'mental disorder'[245] or 'mental illness'[246] or 'mental incapacity.'[247] Notably, both the UNCRPD and the ADP do not define the term 'persons with mental disability'.

In Uganda, the MHA, 2019 adopts the term 'person with mental illness' under section 2 to mean,

> A person who is proven, at a particular time, by a mental health practitioner to have mental illness, at that particular time, and includes a patient.[248]

This thesis prefers to use the term **'persons with mental disabilities'** to include all those suffering from any mental health condition, although the reviewed literature uses terms such as: 'mental health users'; 'mental health survivors'; 'persons with psychosocial and intellectual disabilities', 'persons with mental disorders' or 'persons with mental illnesses'. However, the last two terms are disempowering and perpetuate the medical model of disability by placing emphasis on the impairment alone.

1.12 ORGANISATIONAL STRUCTURE

Chapter 1 provides a background to the state of mental health care in Uganda. The chapter further details the research objectives, research questions, significance of the study, theoretical framework in which the study in premised, the scope, a brief literature review, methodology and operational definitions of the study.

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[245]WHO, 'Mental Disorders' states that mental disorder includes depression, bipolar, schizophrenia and other psychoses, dementia, and development disorder including autism. Mental disorders are generally characterised by a combination of abnormal behaviour, thoughts, emotions, perceptions and relationships with others. The burden of mental disorders continues to grow with significant impact on health and major social, human rights and economic consequences in all countries of the world.

[246] According to Section 2 of the MHA, 2019, mental illness means a diagnosed mental health condition in using accepted diagnostic criteria made by a mental health practitioner authorized to make diagnosis for mental health conditions and includes depression, bipolar, anxiety disorder, schizophrenia and addictive behaviour which is due to alcoholism or substance abuse.

[247] Section 2 of the MHA, 2019 defines mental incapacity to mean the independent and informed cognitive ability to understand the nature and effects of one's decisions and actions.

[248] Section 2 defines a patient as a person who receives treatment and care for mental illness.

Chapter 2 explains the notion of institutionalisation of PWMDs. It briefly traces the origin of the practice, its effects and growth in Uganda. It then examines the transition to the deinstitutionalisation agenda.

Chapter 3 provides an understanding of the right to independent living and community inclusion. It examines the linkage between Article 19 of the UNCRPD and the Convention's other Articles in order to demonstrate the inter-dependency, inter-relatedness, indivisibility of human rights. The Chapter further interrogates the nexus between the provision of Primary Health Care (PHC) and CMHCS and the realisation of the right to independent living and community inclusion. It then discusses the extent of Uganda's progress towards promoting CMHCS.

Chapter 4 explores the legal and policy frameworks on mental health in Uganda and the extent to which they comply with the international and regional standards, and address the need to provide CMHCS. The Chapter further examines the programmatic initiatives in place to support the realisation of the right to independent living and community inclusions for PWMDs in Uganda. It also interrogates the state of CMHCS in Uganda.

Chapter 5 makes a comparative analysis of the state of mental health care, the law and policy frameworks on mental health, the quest for CMHCS and the programmatic measures adopted to promote independent living and community inclusion in South Africa and Kenya, for Uganda to draw best practices.

Drawing from the lessons learnt, Chapter 6 discusses the various strategies that Uganda can adopt to promote the realisation of the right to independent living and community inclusion for PWMDs in the country.

Finally, to provide holistic intervention in the mental health sector, Chapter 7 emphasizes the need for a robust mental health policy and makes proposes for the principles that could be embedded in the policy, and then provides an overall conclusion to the study.

1.13 CONCLUSION

As depicted by the testimonies of Kabale, Komuhanda, Mwase and Mudoola, Uganda is no exception to the deplorable reality of stigmatisation, discrimination, marginalisation, institutionalisation and exclusion faced by PWMDs globally. Institutionalisation in mental health facilities is the main mode of management of PWMDs and their primary route to access to mental health services. As a result, PWMDs are not only excluded from the development agenda,[249] but also disempowered, robbed of their right to individual autonomy, human dignity,[250] and denied the right to independent living and community inclusion.[251] This is contrary to the human rights standards set out in Article 19 of the UNCRPD and Article 14 of the ADP, the UNCRPD Concluding Observations and recommendations made to Uganda, as well as in the domestic legal and policy frameworks.

Following the paradigm shift from the medical model to the social and human rights model of disability embedded in both the UNCRPD and the ADP, State Parties like Uganda have the obligation to enact and/or reform their disability laws and to adopt programmatic measures which conform to the established human rights standards. Community-based mental health care (CMHCS) is one such measure that can be adopted and effectively implemented by Uganda as an alternative to hospital-based institutionalisation. This measure will ease access to mental health services; lead to decongestion of both the national and regional mental health facilities; reduce community stigmatisation; provide better support to families; and will also promote independent living and community inclusion of PWMDs. Hence, this thesis argues that Uganda should embark on the provision of CMHCS in order to promote deinstitutionalisation and the realisation of the right to independent living and community inclusion as guaranteed in Articles 19 of the UNCRPD and 14 of the ADP to PWMDs.

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[249] WHO, 'Mental Health and Development', at 40.
[250] Naggita, 'The Solution is the Problem', at 72.
[251] UNCRPD Committee, General Comment No. 5, para 4.

However, we must first understand the genesis of the practice of institutionalisation of PWMDs and the reasons that propelled the deinstitutionalisation policy. This is discussed in Chapter 2.

CHAPTER TWO

FROM INSTITUTIONALISATION TO DEINSTITUTIONALISATION

2.0 INTRODUCTION

This Chapter provides the origin, rational and application of institutionalisation of PWMDs in Uganda. It then provides an analysis of the deinstitutionalisation agenda. This background is necessary for understanding the vehement call for the transition from institutionalisation to provision of CMHCS and the promotion of the right to independent living and community inclusion reinforced by Articles 19 of the UNCRPD and 14 of the ADP.

2.1 Definition of Institutionalisation of PWMDs

Institutionalisation is premised on the medical model of disability, which promoted voluntary and involuntary admission of PWMDs as the best means of provision of and access to medical care and rehabilitation services.[252] Typically, such institutions are architecturally designed as large buildings, with high strong walls to enhance seclusion of the PWMD, provide therapeutic space and prevent their escape from the institutions.[253] The institutions are often located in remote parts of the country.[254] In institutional care, the requirements or routines of the organisation tend to take precedence over the residents' needs.[255] The UNCRPD Committee emphasizes that,

> Institutionalisation is not just about living in a particular building or setting, it is, first and foremost, about losing personal choice and autonomy as a result of the imposition of a certain life and living arrangement. Neither large-scale institutions with more than a hundred residents nor smaller homes with five to eight individuals, nor even individual homes can be called independent living

[252] EEG, 'Common European Guidelines on Transition', at 26.
[253] Goffman, 'Asylum: Essay on the Situation of mental patients and other inmates', *cited* by Chow and Priebe, 'Understanding Psychiatric Institutionalization', at 3.
[254] *Ibid*, at 3.
[255] EEG, 'Common European Guidelines on Transition', at 10.

> arrangements if they have other defining elements of institutions or institutionalisation.[256]

The UNCRPD Committee has further elucidated that, there are certain defining elements of an institution, such as obligatory sharing of assistants with others and no or limited influence as to who provides the assistance; isolation and segregation from independent life in the community; lack of control over day-to-day decisions; lack of choice for the individuals concerned over with whom they live; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of individuals under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and a disproportionate number of persons with disabilities in the same environment.[257]

In a number of decisions, the UNCRPD Committee has unequivocally held that long-term confinement of PWDs in psychiatric rehabilitation or detention facilities without recognising their legal capacity, affecting due process of the law and the requisite reasonable accommodation measures amounts to institutionalisation, and a violation of their rights to non-discrimination on the basis of disability, exercise of their legal capacity, liberty and security of persons, and independent living and community inclusion. Hence calling on State Parties to replace institutions with community residences. For instance, in *Arturo Medina Vela v Mexico,*[258] the complainant with an intellectual and psychosocial disability was arrested in 2011 for stealing a car. He was denied reasonable accommodation during the various legal processes and eventually committed to a male psychosocial rehabilitation facility for four years, until 2015 when his mother eventually secured his release. Mexico was held to be in violation of Articles 5, 9, 12, 13, 14 and 19 of the UNCRPD. Again, in *Christopher Leo v Australia,*[259] the complainant was a person with psychosocial disability. He was arrested in 2007 and charged with assault of a staff member of

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[256]UNCRPD Committee, General Comment No. 5, Part 11, para 16(c).
[257] UNCRPD Committee, 'Guidelines for Deinstitutionalisation', para 14.
[258] Communication No. 32/2015.
[259] Communication No. 17 /2013.

Tangentyere Council, causing minor injuries and significant mental distress. He was then detained in a high security correction facility, and subsequently transferred to custodial facility, and later relocated to a community residence. He spent a total of nine years in confinement from 2007-2016. The Committee held that, the author was never consulted on his custody and accommodation. The Convention recognizes the right not to be obliged to live in a particular living arrangement, and that institutionalisation as a condition to receive mental health services constitutes differential treatment on the basis of disability. Hence, confining the author to live in a special institution on account of his disability amounted to violation of Article 5 *inter alia*. The State was urged to, *inter alia*, allow the exercise of the right to independent living and be included in the community, taking steps to maximize available resources to create community residences to replace institutionalised settings with support services.

Also, in *Manuway (Kerry) Doolan v Australia,*[260] the complainant who had psychosocial disability was in 2008 arrested and charged with assault on a support worker and damage to property of a supported accommodation facility in which he lived. He was found not guilty by the court due to his impairment and transferred for supervised custody in a high security section of a Correction Centre until 2013 when he was transferred to a custodial facility. In February 2017, he was relocated to a community residence. He alleged violation of his rights under Articles 12, 13, 14, 15 and 19 of the UNCRPD. The Committee held, *inter alia*, that his detention on the basis of his disability in the correction facility was a violation of his rights to liberty enshrined in Article 14. The Committee further urged the State to allow the exercise of the right to live independently and be included in the community by creating community residences to replace institutions.

Prior to the adoption of the UNCRPD in 2006, the African Commission in *Purohit & Moore v The Gambia*[261] had already acknowledged the plight of PWMDs in

[260] Communication N0.18/2013.
[261] Para 68.

institutionalisation or detention. In determining the issue whether the long term confinement of persons with mental illness in mental facilities under the Lunatics Detention Act was contrary to the right to liberty enshrined in Article 6 of the ACHPRs. The Commission held that, although Article 6 of the ACHPRs was not intended to cater for situations where persons in need of medical assistance or help are being institutionalised, institutionalisation of such persons under the Lunatic Detention Act with no avenue for review or appeal in case of wrong diagnosis being made falls short of international standards and norms.

This implies therefore, is now an unacceptable practice. In addition, no matter the size of the building, it is an 'institution' if the PWMDs are restricted in movement; or if their right to exercise their free will, choice and preferences over any matter that affects their lives is curtailed. Institutionalisation often results in isolation and exclusion of PWMDs from their families and local communities.[262] Hence, violating not only their right to liberty, but also, independent living and community inclusion.

The next section provides a brief historical overview on the growth of institutionalisation of PWMDs in Britain, Uganda's former colonial master. The impact of British policy during the colonial era is still evident in contemporary Uganda, where institutionalisation remains part of the framework for PWMDs, and it is therefore necessary to understand the historical background.

2.2 Historical overview of Institutionalisation of PWMDs in Britain

Writing within the context of the United States and Netherlands, Morrissey and Goldman, and Ravel respectively attribute the growth of institutionalisation of PWMDs by the 1870s to the growth of industrialisation and the need to provide custodial care to PWMDs as well as community protection.[263] In Britain, however, institutionalisation of PWMDs dates back to 1247 when a priory, which became the Bethlem hospital in 1330, was constructed to provide shelter for the sick and

[262]European Union Agency for Fundamental Rights (EUAFR), 'Choice and Control', at 13.
[263] Morrissey and Goldman, 'Care and Treatment', at 15; Ravelli, 'Deinstitutionalisation of Mental Health care', at 1-2.

infirm.[264] As the level of institutionalisation in 'asylums' grew, so did the legislation, which developed from the 1890 Lunacy Act to the 1930 Mental Treatment Act. Both instruments permitted the confinement of patients in asylums which were often built in the outskirts of the city in order to isolate both the patients and the psychiatrists working there from the local communities.[265] By the end of 19th century, there were as many as 120 asylums in England and Wales housing more than 100,000 PWMDs.[266]

Evidently, industrialisation in the western world propelled the practice of institutionalisation of PWDs who were disabled and considered not useful for the emerging industrialised economy.[267] A further factor was the influence of the eugenics movement which advocated for the institutionalisation and sterilisation of PWDs to prevent them from procreating so as not to reproduce similarly 'defective' children and also to 'purify' the human race.[268] The eugenic movement, coupled with the Charles Darwin's theory of evolution[269] and the Bell Curve theory,[270] together influenced the growth of medical model of disability.[271] This perpetuated the marginalization, segregations and institutionalization of PWMDs.[272]

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[264] Killaspy, 'From the Asylum', at 246; Jarret, 'Disability in Time and Place', at 10.
[265] *Ibid*, at 247.
[266] Jarret, 'Disability in Time and Place', at 29.
[267] Oliver, The Politics of Disablement', at 38, *cited* by Naggita, 'The State and the Law', at 36-38; Jarret, 'Disability in Time and Place', at 28-29.
[268] Schur, Kruse and Blanck, *Sidelined or Mainstreamed?* at 122; Kanter, *Development of Disability,* at 66 observed that, overtime, institutions were considered inadequate in isolating the cause of society's problems. As a result, eugenics was born. The policies of eugenicists required that in order to preserve the "purity" of the human race, people who were considered unfit, primarily owing to the mental state and intellectual disability, should be sent away to institutions and forcibly sterilized.
[269] Davis, 'The Disability Studies Reader', at 3.
[270] Also referred to as the 'Normal Curve Theory' or the 'Normal Distribution Curve' which emphasized that those whose IQ was far away (deviate) from the mean (center) from the low (deviant) or high end (extremes) where not within the normal. The Bell curve Theory was developed by Richard. J. Herrnstein and Charles Murray in 1994 in their book titled 'The Bell curve'.
[271] Lawson and Priestley, 'The Social Model of Disability', at 6.
[272] Walmsley, 'Institutionalisation', at 5.

2.3 Colonialism and Institutionalisation in Uganda

Prior to colonialism, institutionalisation of PWMDs was unknown in Uganda. African societies largely relied on family care, traditional medicine and healing for the treatment of many ailments including mental illness.[273] However, by the late 19th century, the practice of institutionalisation of PWDs had gained roots in the developed countries, and it was subsequently imported into Africa through colonialism.[274] Some scholars contend that institutionalisation was used as a tool to control Africans who resisted colonial rule, and to maintain western superiority.[275] Fermando opined that, it is very likely that 'asylum-psychiatry' introduced in sub-Saharan Africa by British colonizers was peripheral to mental health needs of the people in the area. The 'asylums' may well have served a social control function allied to colonial subjugation but certainly not a therapeutic one.[276] Africans who resisted colonial rule found themselves confined in asylums.[277]

In Uganda, the practice of institutionalisation of PWMDs emerged by virtue of colonialism.[278] After the wave of independence in the 1960s, former colonies such as Uganda, which had previously adopted colonial laws and medical practices, continued the practice of institutionalisation.[279] This was bolstered by the promulgation of several laws which emphasized institutionalisation of PWMDs, namely: the Mental Treatment Ordinance (MTO) N0. 5 of 1938, which was repealed

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[273] Modie-Moroka, 'Mental health services in Botswana', at 11. Kenyan documentary titled*: 'Locked up and Forgotten'*¿ Naggita, 'The State and the Law', at 97; Jackson, 'Surfacing up', at 127; Fermando, 'Mental Health Worldwide', at 74; Alem, 'Community-based vs Hospital-based mental health care', at 98.

[274] The WHO, *World Health Report*, at 49; Naggita, 'The State and the Law' at 97; Modie-Moroka, 'Mental health services in Botswana' at 11; Fermando, *Mental Health Worldwide*, at 73-75. Fermando reports that the first asylum in British West Africa was established in Sierra Leon in 1844, followed by Accra Lunatic Asylum in Gold Coast (now Ghana) 1888, and Yaba Asylum in Nigeria in 1906, and later Mathari Hospital in Kenya.

[275] Li Zheng, 'Colonial Psychiatry in Africa', at 9¿ Megan, 'Caring for the ills', at 125, *cited* by Modie-Moroka, 'Mental health services in Botswana', at 15; McCulloch, *Colonial Psychiatry and the African mind*, at 167; Swartz, 'Madness and Methods', at 70-74; Fermando, *Mental Health Worldwide,* at 75.

[276] Fermando, *Mental Health Worldwide,'* at 75.

[277] Swartz, 'Madness and Methods', at 70-74; Fermando, *Mental Health Worldwide,* at 75.

[278] Naggita, 'The State and the Law', at 97; Cappo, Mutumba and Verity: 'Belonging home', at 61.

[279] Modie-Moroka, 'Mental health services in Botswana', at 15; Oley, 'Culture and Mental illness', at 20-22; Mulumba, 'Analysis of the MTA', at 2; Kabale, 'A Critical Overview,' at 2.

by the Mental Treatment Act Cap 270 of 1938, which was further repealed by the Mental Treatment Act (MTA) Cap 279 of 1964.[280] Furthermore, the growth of institutionalised mental health care led to the eventual establishment of the infamous Hoima prison in 1927, followed by a mental health unit in Mulago Hospital in 1934,[281] and subsequently the establishment of Butabika National Referral Mental Hospital in 1955 (commonly referred to as 'Butabika Hospital') with a bed capacity of 550 patients.[282] Kigozi, Ssebunya and Kizza observed that the language used in reference to PWMDs, as well as the architectural designs of the mental health institutions perpetuated stigma by the colonial government.[283]

For a long time, all mental health patients from across the country were referred for treatment to Butabika and Mulago hospitals, until the recent opening of psychiatric wards at various regional referral hospitals. The Ministry of Health (MoH) confirms the availability of mental health services at National Referral Hospitals, Regional Referral Hospitals and all other health facilities in the country.[284] MDAC and MHU reports that, there are now thirteen regional referral hospitals with mental health units. These are located in Arua, Fort portal, Gulu, Hoima, Jinja, Kabale, Lira, Mbale, Mbarara, Moroto, Mubende and Soroti.[285] The bed capacity of the mental health units of the regional hospitals ranges from 16 to 40 beds, and each unit attends to between 170 and 360 inpatients per year. In terms of out-patients,

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[280]Mulumba, *ibid*; Twinomugisha, *Fundamentals of Health Rights*, at 136-137; Nyombi, Kabandama and Kaddu, 'A Critique of the MTA, 1964', at 507; Kabale, 'A Critical Overview' at 2; Mulumba, Ruano, Perehudoff and Ooms, 'Decolonizing Health Governance', at 266.

[281] Mulumba, *ibid*; Nyombi, Kabandana and Kaddu, *ibid*, at 507; Nsereko, 'The Evolution of Mental Health', at 1.

[282]WHO proMIND, 'Profile on Mental Health in Development: Uganda', at 44; Nyombi, Kabandana and Kaddu, *ibid*, at 508; Mulumba, *ibid*, at 2-3.

[283] Kigozi, Ssebunya, Kizza, Green *et al*, 'A Situation Analysis', at 51.

[284] See Ministry of Health (MoH), 'Draft National Policy for Mental Health, Neurological and Substance Abuse Services (2011) at 7 (copy available with author); and Ministry of Health, 'What you need to know about Mental health.' Available at https://www.health.go.ug/cause/what-you-need-to-know-about-mental-health/. (Accessed on 1st December 2022).

[285] MDAC and MHU, 'Psychiatric hospitals', at 22 reveals that Arua hospital was established in 1938 and the mental health unit established in 2005; Mbale Hospital was constructed in 1920 and the mental health unit in 2009; Gulu Hospital was constructed in 1934 and mental health unit in 2004; Soroti Hospital was constructed in 1943 together with the mental health unit; Kabale Hospital was constructed in 1941, and Mbarara Hospital in 1940.

regional referral hospitals provide between 748 to 2,500 consultations per year.[286] However, due to data limitations, it is difficult to determine the total length of stay in the facility by the in-patients.[287]

Although medical intervention remains pertinent—even in Uganda—to address the negative effects of the impairment on the life of a PWMDs, embarking on alternative interventions like provision of CMHCS, community support services (CBS) and deinstitutionalisation programme must be intensified so as to curtail institutionalisation of PWMDs in the country.[288]

2.4 The Consequences of Institutionalisation of PWMDs

Historically, institutionalisation was seen as the means for provision of and access to medical care and rehabilitation services for PWMDs in a 'therapeutic space'[289]and for protecting property and the society from dangerous PWMDs.[290] The medical model did not place emphasis on community-based mental health care and services, resulting into institutionalisation for long periods of many PWMDs.[291] Consequently, instead of offering treatment and rehabilitation of PWMDs, the institutions became 'warehouses' where PWMDs were mistreated, neglected and abused.[292] In most cases, they were characterised by inadequate medical care,[293] overcrowding and poor hygiene, which resulted in reduced therapeutic care[294] and

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[286] *Ibid,* at 11.
[287]*Ibid*, at 30; WHO, 'AIMS Report: Mental Health systems in Uganda,' at 11; Kigozi, Ssebunya, Kizza, Green *et al*, 'A Situation Analysis', at 67-68; Molodynski, Cusack and Nixon, 'Desperate challenges', at 98; WHO, 'Mental Health Atlas', at 81 reveals the length of time of stay in institutional or residential care globally. For African countries, 94% of residential care is for over 1 year, 2% for between 1-5 years, and 6% for stay for less than 5 years.
[288] Twinomugisha, 'Health and Human Rights Critique,' at 15; Twinomugisha, *Fundamentals of Health Law*, at 136; Cappo, Verity and Mutumba, 'Belonging home', at 61.
[289] Chow and Priebe, 'Understanding psychiatric institutionalization', at 4.
[290] Kanter, *The Development of Disability*', at 65-67.
[291] EEG, 'Common European Guidelines on Transition', at 10.
[292] Kanter, *The Development of Disability*, at 65-67; Owen, Tarantello, Jones, Tennat, 'Violence and Aggression', *cited* by Chow and Priebe, 'Understanding psychiatric institutionalization', at 8; WHO, *World Health Report*', at 47-49.
[293] Mental Disability Rights International (MDRI), 'Torment not Treatment', at 149-157.
[294]Albert Deutsch, 'The Mentally ill in America', *cited* by Morrissey and Goldman, *Care and Treatment of the Mentally ill in the US*, at 17.

neglect, and led to an increase in violations of the human rights of PWMDs in the facilities.[295]

In addition, institutionalisation leads to restriction of liberty, limited access to justice, limited family life, limited access to education and employment, and limitations on the opportunity to participate in political and public life.[296] However, in circumstances where institutionalisation of a PWMDs must occur for purposes of administering medical intervention, it is contended that this should be in the shortest period of time possible, in least restrictive, secure and healthy environment, in a manner which protects the human dignity of the PWMD, and with the necessary individualised support to allow for eventual community reintegration.[297]

Consequently, institutionalisation leads to isolation due to limited access to the outside world and the individual's loss of independence and personal autonomy, which undermines their ability to live outside the institution and to manage everyday demands.[298] This is an abuse of human rights.[299]

These challenges confirm the argument that institutionalisation invariably produces poorer outcomes than high-quality services in the community.[300] The UNCRPD Committee has emphasized that the cost of social exclusion is high as it perpetuates dependency [on the institution] and thus interferes with individual

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[295] UNOHCHR, *Forgotten Europeans: Forgotten Rights*, at 6.
[296] Laikind, 'The Application of Article 12', at 17; The UNCRPD also found a violation of these rights in the following decisions *Christopher Leo v Australia; Arturo Medina Vela v Mexico*; *Munir al Adam v Saudi Arabia* CRPD/C/20/D/38/2016; *Marlon James Noblev Australia* CRPD/C/16/D/7/2012.
[297]Parry, 'Mental and Physical Disability Rights', at 628. This is the rationale under section 24(11)-(13) of the MHA, 2019. Sub-section (11) which provides for the involuntary admission of a patient with mental illness, where it is the only means by which that persons may be provided with care, treatment and rehabilitation that will benefit him or her. Such involuntary admission shall be for a period of not more than three months unless the Mental Health Advisory Board authorizes extension of period.
[298] WHO, 'Innovations in Deinstitutionalisation', at 16; WHO, 'QUALITYRIGHTS: Service standards and Quality', at 4; WHO, *Mental Health, Human Rights and Standards of Care*, at 4.
[299] UNOHCHR, *Forgotten Europeans: Forgotten Rights*, at 9; Perlin, 'When the silenced are heard', at 18.
[300] WHO, 'Pyramid Framework', at 2; Mansell *et al*, *Deinstitutionalisation and community living – outcomes and costs*, at 97; EEG, 'Common European Guidelines on Transition', at 21; UNCRPD Committee, General Comment No.5, para 5.

freedoms, engenders stigma, segregation and discrimination, which can lead to violence, exploitation and abuse, in addition to the negative stereotypes that feed into a cycle of marginalization (and exclusion) against PWDs.[301]

It is these negative ramifications of institutionalisation that set the stage for the deinstitutionalisation policy and the impetuous towards the promotion of community mental health care and support to enable independent living and community integration of PWMDs.[302]

2.5 The Shift to Deinstitutionalisation

According to the WHO, deinstitutionalisation process is a planned and gradual transition from a predominantly institutionally-based service model to a model that provides treatment and care through available community services, general hospitals, and most importantly through primary health care.[303] To Ravelli, deinstitutionalisation is the transfer of mentally ill people from State hospitals into the community, their diversion from hospital admission and the development of alternative community services.[304] Deinstitutionalisation is a critical strategy in enhancing human rights protection for PWMDs.[305] The UNCRPD Committee guides that, deinstitutionalization comprises interconnected processes that should focus on restoring autonomy, choice and control to persons with disabilities as to how, where and with whom they decide to live.[306] Further, that all PWDs have the right to live in the community, and it is discriminatory to decide that some people cannot live in the community and should stay in institutions.[307]

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[301]UNCRPD Committee General Comment No.5, (2017), para 5.
[302] Owen, Tarantello, Jones, Tennat, 'Violence and Aggression', at 8; WHO, 'Innovations in Deinstitutionalisation', at 16; WHO, *Mental Health, Human Rights and Standards of Care*, at 12; WHO, 'Mental Health Action Plan 2013-2020'; WHO, 'Pyramid Framework', at 2.
[303] WHO, 'Pyramid Framework', at 2.
[304] Ravelli, 'Deinstitutionalisation in the Netherlands', at 8.
[305] ENIL, 'Barriers to Independent Living', at 8.
[306] UNCRPD Guidelines on Deinstitutionalisation: Para 19-20.
[307] *Ibid,* para 37.

The deinstitutionalisation policy was a major component of mental health care in the 20th century, and led to the downsizing of many psychiatric hospitals and the opening of community-based, open and decentralized mental health services in Europe.[308] Parker, Chow and Priebe, and Pedersen and Kolstad argue that the shortcomings of institutionalisation led to the adoption of deinstitutionalisation policy, and that this was attributed to: the rise of the civil rights movement and the advocacy for the right to receive treatment in the least restrictive environment possible; the advent of effective antipsychotic medication; the growing wave of public antipathy towards psychiatric institutions as the abuses and poor conditions became more widely known; the growth of mental health users / survivor groups and the development of disability activism; an assumption that community-based care would be more humane; and a variety of political arguments emanating both from a the human rights perspective and from financial imperatives driven by growing costs of institutionalisation, and the perception that community-based care would be cheaper.[309]

Mansell, Knapp, Beadle-Brown *et al*,[310] and McCarson, Vance, Murphy *et al* agree that deinstitutionalisation promotes a better quality of life for PWMDs, since it enables: freedom and independence in managing ones' own life in the community; better compatibility with co-residents; more supportive staff who help to improve individuals' participation and inclusion in the community; improved social integration and contact with the families; and increased access to services in the community; [311] as well as improved treatment and care, and upholding the human rights of PWMDs.[312] The recognition of the shortcomings of institutionalisation vis-à-

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[308] Pedersen and Kolstad, 'De-institutionalisation and trans-institutionalisation', at 2; Fermando, 'Mental Health Worldwide', at 85.
[309]Parker, 'De-institutionalisation in Psychiatry', at 104; Chow and Priebe, 'Understanding psychiatric institutionalization', at 2; Pedersen and Kolstad, 'De-institutionalisation and trans-institutionalisation', at 13; Ravelli: 'Deintitutionalisation in the Netherlands', at 2; Yohana, 'Causes and consequences', at 886; WHO, *World Health Report*, at 49.
[310] Mansell, Knapp, Beadle-Brown *et al*, 'Deinstitutionalisation and community living', at 229.
[311]McCarron, Vance, Murphy *et al*, 'Effects of Deinstitutionalisation on the quality of life', at 9-12.
[312] Salisbury, Killaspy and King, 'An International Comparison of the Deinstitutionalisation', at 1; UNCRPD Guidelines on Deinstitutionalisation: para 19-20.

vis the benefits of deinstitutionalisation has resulted in some countries[313] adopting the latter as a policy to allow PWMDs leave institutions and to live in the community in a more dignified manner.[314]

However, it must be emphasized that an effective deinstitutionalisation strategy requires several elements and processes. First, a shift away from State's reliance on psychiatric hospitals in their mental health care programmes. Second, an increase in the number of mental health beds in general hospitals; and third, the growth of community-based inpatient and outpatient services for PWMDs.[315] The WHO notes that deinstitutionalisation is a long-term complex strategy than simply reducing long-stay beds, and that it also ensures that good-quality care is available in community settings and it shifts tertiary resources towards acute inpatient services and accessible secondary-level mental health services.[316] In addition, the WHO emphasizes the:[317]

> a) availability of skilled, trained, well-motivated and committed mental health workers who are ready to deliver community-based mental health services in the communities;
>
> b) availability of adequate budgetary/ financial support to ensure that policies, legislations and plans are well implemented;

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[313] *Ibid*, at 7, lists countries like United Kingdom, Finland, Italy, Iceland, Ireland, Belgium as highest ranking in the deinstitutionalisation process.

[314]Karter, *The Development of Disability*, at 67; Chow and Priebe, 'Understanding psychiatric institutionalization', at 2; Ravelli, 'Deinstitutionalisation in the Netherlands' at 3-4; EEG, 'Common European Guidelines on Transition' at 21; WHO, 'Innovations in Deinstitutionalization', at 17.

[315]Pedersen and Kolstad, 'De-institutionalisation and trans-institutionalisation', at 2; Becker and Va'zquez-Barquero, as *cited* by Ravelli, 'Deinstitutionalisation in the Netherlands', at 2 opine that, ''Psychiatric reform is not just about abolishing the old fashioned psychiatric institutions but also concerns a number of issues such as: legislation, attitudes of society towards psychiatry, the choice of the scale of the catchment area for alternative facilities, the realisation of new facilities, the roles of other care suppliers such as the GP, the welfare sector, the general health care services, the balance and financing of the care, the fate of the patients coming from the old-fashioned institutions, the way to cope with the ever-increasing demand for psychiatric help and finally the actual quality of psychiatric help.''

[316] WHO, 'Innovations in Deinstitutionalization', at 17.

[317]*Ibid*, at 30-35, 40; UNCRPD Committee, General Comment No. 5, para 33.

> c) There must be substantial support for deinstitutionalisation process and resort to the provision of community-based mental health care services by the various stakeholders including the community;
>
> d) Timely establishment of community-based services before discharge of long-term institutionalised patients;[318] and
>
> e) The presence of political skill and will, and commitment to foster deinstitutionalisation process.

Despite the benefits of deinstitutionalisation, it must be acknowledged that there are some patients who by the nature of the severity or acuteness of their mental illness will not be able to cope in community-based care and who will still require hospitalisation or institutionalisation.[319] In such cases, it is argued that institutionalisation should be a matter of last resort, for the shortest period of time, in the least restrictive environment, with absolute adherence to human rights standards, and for the most severe or acute cases.[320] As Parry argues:

> Deinstitutionalisation does not mean releasing everybody in the institutions on the streets, but rather ensuring that the mental hospitals are humane and for those who need treatment, applying the least restrictive alternative and for the shortest period of time.[321]

Similarly, while advocating for a transition from institutionalisation to promotion of CMHCS before the Parliamentary Sectoral Committee on Health on the Mental Health Bill, 2014 (now MHA, 2019), the Initiative for Social Economic Rights (ISER) contended that:

> Given that the process of continued involuntary admission denies persons with psychosocial disabilities the autonomy to make decisions and live independently as guaranteed in Article 19 of the UNCRPD, it is essential that it is only done to the most severe of cases and in instances where it is done, procedural safeguards should be put in

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[318] Talbott, 'Deinstitutionalisation: Avoiding the disaster of the Past', at 1114 opined that, community support system is a system of support that enables the chronically mentally ill persons to receive the treatments and services he would not receive if he were housed in a total institution.

[319] Walmsley, 'Institutionalisation', at 9; Chow, Ajaz and Priebe, 'What drives changes in Institutionalised mental health care?', at 741.

[320] WHO, 'Innovations in Deinstitutionalization', at 17.

[321] Parry, 'Mental and Physical Disability Rights', at 628; UNOHCHR, 'Forgotten Europeans: Forgotten Rights', at 10; Lamb and Linda, 'The Shift of Psychiatric Inpatient care', at 534.

> place and the system should be as formal and as transparent as possible to safeguard the rights of persons with psychosocial disabilities.[322]

In conformity with the above argument, section 24 (11) of the MHA, 2019 provides that, 'A person shall only be admitted as an involuntary patient where involuntary admission is the only means by which that person may be provided with care, treatment and rehabilitation that will benefit him or her.'[323]

This approach prevents severely mentally ill persons from 'falling between the cracks', and also avoids trans-institutionalisation[324] or the 'revolving door' phenomenon.[325]

2.6 Conclusion

Evidently, institutionalisation of PWMDs was, and still is, an entrenched practice in both developed and developing countries. In view of its negative consequences, it is clear that the transition to the deinstitutionalisation policy was timely and that it must be embraced and implemented by all States. These efforts, if adequately and strategically concretised, will lead to the decongestion of mental health facilities, pave the way for provision of CMHCS services, and also enable PWMDs enjoy the right to independent living and community inclusion as enshrined in both Article 19 of the UNCRPD and 14 of the ADP.

Notably, the new MHA, 2019 laudably recognises the need for CMHCS and provision of mental health treatment at primary health centres within reach to the

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[322] Initiative for Social Economic Rights (ISER), 'Analysis of the Mental Health Bill, 2014', at 6.
[323] As a safeguard to long-stay institutionalisation, Section 24(12) provides that involuntary admissions shall be for a period of not more than three months, unless the Mental Health Advisory Board authorizes extension of the period.
[324] Prins, 'Does Transinstitutionalization', at 720.
[325] Talbott, 'Deinstitutionalisation: Avoiding the disaster of the Past', at 1113. 'Falling between the cracks' refers to a total lack of follow-up, and thereafter of discharged patients, and 'revolving door' refers to their continued readmission. That is, patients spent fewer days in hospital but accounted for many more in admissions and readmissions to a larger number of hospitals, with shorter length of stay for each admission. Hence resulting into trans-institutionalisation as opposed to deinstitutionalisation. See also, Chow, Ajaz and Priebe, 'What drives changes in Institutional mental health care', at 741.

'person with mental illness'.[326] It also provides for various modes of admissions of a 'person with mental illness' to protect him or her from death, inflicting injury to himself or herself, or inflicting injury to others, or damaging property. These modes include: emergency admission;[327] assisted admission;[328] and voluntary[329] and involuntary admission.[330] In an attempt to guard against institutionalisation or long-term stay in the mental health facility, the MHA, 2019 commendably sets timelines within which a person admitted in the facility should be treated and discharged.[331] Such period can only be extended by the Mental Health Advisory Board,[332] following a written application made by the medical practitioner. Given that the MHA, 2019 is a new legislation, it is hoped that eventually these progressive provisions will be adhered to so as to enhance access to mental health services within the communities, as well as promote deinstitutionalisation and protection of the rights of PWMDs that are susceptible to abuse during institutionalisation.

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[326] Sections 3(f) and 20 respectively of the MHA,2019.

[327] *See*, Section 22. Emergency admission arises where a relative, concerned person or police officer suspects that a person is suffering from a mental illness and causes the person to be admitted in a health unit or mental health unit for emergency treatment.

[328] *See,* Section 30. Assisted admission occurs where a person is taken by a relative or concerned person to the health unit or mental health facility for assisted admission and treatment.

[329] *See,* Section 29. Voluntary admission occurs where a person who is eighteen years and above (adult) voluntarily submits himself or herself for admission and voluntary treatment in a health unit or mental health facility. For children, such voluntary admission can be made by their parent(s) or guardian.

[330] *See,* Section 24. Involuntary admission occurs where a person with mental illness and prima facie requires treatment and care from a mental health unit but is for the time being incapable of expressing himself or herself as willing or unwilling to receive treatment. Such a person may, on a written request made by a relative, or a concerned person, be admitted as an involuntary patient.

[331] *See,* Section 22(9). For emergency treatment, it should not exceed five days. Section 24(12) provides that involuntary admission shall be for a period not exceeding three months. Section 26 also permits the medical practitioner to grant an involuntary patient a leave of absence from the mental health facility. Section 31 allows for the discharge of a person on assisted admission upon the request for discharge by the relative or concerned person who caused his/ her assisted admission and is willing and able to take care of the 'patient'. Section 29(4) allows a voluntary patient to leave the health unit or mental health facility upon giving an officer in charge of the unit a seventy-two hours (that is, three days) notice of his or her intention to leave.

[332] Established under section 5 of the MHA, 2019. Its functions as spelt out in section 9 include: (b) monitoring the implementation of the Act; and (e) reviewing any matters referred to it by a patient, relative, or a concerned person concerning the treatment of the patient in the mental health unit...and advise mental health units on the necessary steps to take or remedial action.

CHAPTER THREE

INTERNATIONAL AND REGIONAL NORMS ON THE RIGHT TO INDEPENDENT LIVING AND COMMUNITY INCLUSION FOR PWMDs, AND THE CASE FOR COMMUNITY-BASED MENTAL HEALTH CARE IN UGANDA

> *PWDs are often excluded from community life, stigmatized and discriminated against in the fields of employment, education, housing and social welfare on the basis of their disability. Many are denied the right to vote, marry and have children. These violations not only prevent people from living the lives they want, but also further marginalize them from society, denying them the opportunity to live and be included in their own communities on an equal basis with everyone else.*[333]

3.0 Introduction

Article 19 of the UNCRPD and Article 14 of ADP guarantee the rights of all PWDs to independent living and community inclusion. Hence, State Parties to the UNCRPD are obliged to ensure that all PWDs realise these rights. The UNCRPD Committee unequivocally held in *Simon Bacher v Austria* that, State Parties undertake to ensure and promote the full realisation of all the fundamental human rights for all PWDs without discrimination of any kind on the basis of disability. To that end, State Parties must take all appropriate measures to eliminate discrimination on the basis of disability by any person, organisation or private enterprise. Therefore, the State Party's argument that the communication deals with a dispute that is exclusively between individuals, and therefore does not fall under the Convention does not hold.[334]

This thesis argues that promoting CMHCS for PWMDs within a comprehensive Primary Health Care (PHC) system is a State obligation and a key factor in enabling the realisation of the right to independent living and community inclusion. For a holistic understanding what the right to independent living and

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[333] WHO, 'Guidance on Community mental health Services', at 3.
[334] *Simon Bacher v Austria*, Communication No.26 of 2014; Arturo Medina Vela v Mexico, Communication No. 32 /2015.

community inclusion entails, this chapter briefly traces the history of the independent living movement, defines the concept of independent living and community inclusion, unpacks the core elements of the right to independent living and community inclusion as enshrined in both the UNCRPD and the ADP, and demonstrates the interconnectivity between these rights and several other human rights in the UNCRPD and other international and regional instruments.[335] The chapter also makes the case for an effective PHC system infused with the provision of CMHCS in Uganda, in order to enhance access to mental health treatment, care and support at community level hence promoting deinstitutionalisation, independent living and community inclusion for PWMDs. It examines the progress Uganda has made in the provision of CMHCS, and then final reflections in the conclusion.

3.1 The Struggle for Independent Living

Independent living is also referred to as living independently, or community living, or supported living.[336] The struggle for independent living preceded the UNCRPD.[337] It can be traced historically to the movement led by Ed Roberts in Berkeley, California in the 1960s-70s.[338] The movement was spearheaded by a few individuals with severe disabilities who required assistance with the activities of daily living. They were inspired by the civil rights struggles of Black Americans and

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[335] These include: the UDHR, ICCPR, ICESCR, CAT, CEDAW, ACHPRs, Maputo Protocol and the ACRWC that preceded the UNCRPD. The rights and freedoms guaranteed in these instruments must be enjoyed by all PWDs since they too are part of the human race and with human diversities.

[336] Fox, 'What's Fair?!', at 32 confirms that independent living is often termed as 'community living' or 'supported living', although the core of the concept remains the same, being about equality of choice, self-determination, access to same services and facilities as all other citizens and support to enable access. See also, Parker and Clements, 'The UNCRPD: A new right to independent Living?', at 2; Kamundia, 'Choice, Autonomy and Support', at 45.

[337] Brennan, 'Article 19 and the Nordic Experience', at 157; Parker and Clements, 'A New right to Independent living', at 4.

[338] Schur, Kruse and Blanck, *Sidelined or Mainstreamed*? at 122. Roberts—a quadriplegic student in the University of California—was forced to live in the university hospital while attending college. He then organised other students at the university into a group called 'Rolling Quads', which protested the institutionalisation and then established the first Center for Independent Living (CIL). The Berkeley CIL became a model that inspired the creation of other CIL in the United States and throughout the world.

other groups that campaigned for equal rights and resisted discrimination.[339] The most important demand of the independent living movement was that PWDs must have the same degree of self-determination and freedom of choice like all human beings so as to realise their right to independent living.[340] This campaign led to the paradigm shift adopted in Article 19 of the UNCRPD.[341]

3.2 The Right to Independent Living and Community Inclusion

3.2.1 The right to Independent Living

The term 'Independent living', also referred to as 'community living',[342] is not expressly defined in the UNCRPD or the ADP. Parker and Clements explain that independent living is not about PWDs living highly individualised and independent lives in isolation of others, but rather eradicating social barriers that disable PWDs, and providing support measures that enable and empower them to exercise autonomy, choice and control over their lives and daily living arrangements like their non-disabled counterparts, thus enabling them to participate meaningfully in society and preventing isolation or exclusion.[343]

According to the UNCRPD Committee,

> Independent living or living independently means that individuals with disabilities are provided with all necessary means enabling them to exercise choice and control over their lives and make all decisions concerning their lives. Personal autonomy and self-determination are fundamental to independent living, including access to transport, information, communication and personal assistance, place of

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[339]Ratzka, 'Independent Living Movement'; Scotch, 'Politics and Policy in the History of Disability Rights', at 380-400; Brennan, 'Article 19 and the Nordic Experience', at 157; Fox, 'What is Fair?', at 147.
[340] *Ibid.*
[341] *Ibid.*
[342]European Coalition for Community Living (ECCL), 'Focus on Article 19 of UNCRPD', at 6, observed that community living refers to people with disabilities being able to live in their local communities as equal citizens, with the support that they need to participate in every-day life. This includes living in their own homes or with their families, going to work, going to school and taking part in community activities.
[343] Parker and Clements, 'A New right to independent living', at 2; Brenan, 'Article 19 and the Nordic experience', at 157; European Union Agency for Fundamental Rights (EUAFR), 'Choice and Control', at 14.

> residence, daily routine, habits, decent employment, personal relationships, clothing, nutrition, hygiene and health care, religious, cultural and sexual and reproductive rights. These activities are linked to the development of a person's identity and personality...Independent living is an essential part of the individual's autonomy and freedom, and does not necessarily mean living alone. It should also be interpreted solely as the ability of carrying out daily activities by oneself.[344]

Arguably, independent living is based on the premise that people — including even the one with the most severe disability — should have choice of living in the community.[345] The core elements of independent living include: individual autonomy, choice, control, an enabling environment, equal access to social amenities, and participation in society on an equal basis with others.[346]

In comparison, Article 14 of the ADP uses the term 'living in the community'. It provides that, every person with a disability has the right to live in the community with choices on an equal basis with others.[347] It then spells out a broad spectrum of measures that State Parties should undertake to realise the right to live in the community for PWDs as discussed in section 1.2 above.

It is therefore unequivocal that to realise the right to independent living [community living] all PWDs must be enabled to exercise their choice, free will and personal autonomy and be supported through the availability of appropriate support mechanisms, social amenities and an enabling physical and attitudinal

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[344]UNCRPD Committee, General Comment No. 5, Part 11, paras 16(a) and 16(c); UNCRPD Guidelines on Deinstitutionalisation: Para 23 provides that, a core element of living independently and being included in the community is that all persons with disabilities have the support, based on their own choices, that they may require to carry out daily activities and participate in society. Support should be individualized, personalized and offered through a variety of options. Support encompasses a wide range of formal assistance, as well as informal community-based networks. See further Para 99-106 providing for the various actions States must take to realise the right to independent living for all PWDs.

[345] Kamundia, 'Choice, Support and Inclusion', at 49.

[346] *Ibid*, at 56.

[347] Article 14(1).

environment.[348] Social barriers that hinder the accessibility and enjoyment of this right must be eradicated. Quinn and Stein opine that,

> Article 19 is the result of the CRPD's revolution of ideas, and provides the alternative vision and positive counterpoint to the devastating and unacceptable circumstance of institutionalisation.…States parties are tasked with creating the means through which persons with disabilities are able to become integral parts of their societies so that they can flourish through collective activities. This is a direct remedy to the historical treatment of disabled persons through programmes that isolated and exploited them, and denied entire segments of society the ability to explore and exercise their talents.[349]

Similarly, Degener emphasized that premised within the social model of disability, the concept of independent living strongly opposes the medical rehabilitation paradigm of disability and rejects institutionalisation or similar systems promoting dependency of disabled individuals on institutions[350]

Consequently, State Parties to the UNCRPD and now the ADP must adopt measures that bring an end to the practice of institutionalisation of PWMDs in any institution-like facility. This thesis argues that provision of CMHCS integrated within the PHC system is one of the necessary measures for achieving this goal and for realising the right to independent living and community inclusion of PWMDs in Uganda. However, it must be emphasized that institutionalisation, as a matter of last resort, in the least restrictive environment and for the shortest period of time,

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[348] Article 12 and General Comment No.1 of UNCRPD; UNCRPD Guidelines on Deinstitutionalisation: para 21.24, 69 and 80; *Christopher Leo v Australia* Communication No.17/2013; H.M V Sweden Communication No.3/2011; *Simon Bacher v Australia,* Communication No.26/2014*; Manuway(Kerry)Doolan v Australia*. Communication No.18 of 2013 all emphasizing the need to provide PWDs reasonable accommodation measures to enable them exercise their legal capacity and enjoy the rights in the convention.

[349]Quinn and Stein, 'Challenges of community living', at 28; Kanter, '*The Development of Disability*', at 107.

[350] Degener, 'Disabled People', at 14.

remains relevant to manage persons with acute or severe mental conditions that cannot be managed in the community.[351]

3.2.2 The Right to Community Inclusion

3.2.2.1 Understanding the terms 'community' and community inclusion'

Full and effective participation and inclusion of PWDs in the community is one of the cardinal principles of both the UNCRPD and ADP.[352] However, neither instrument provides an interpretation of the term 'community'. Kanter defines a 'community' as a group of people living together in a specific area or geographical location who may or may not share common values, identity or experiences.[353] A community also connotes a sense of belonging, which is key to formation of one's identity and rights to participate in the community.[354] This thesis adopts the definition that a community is a group of people living together in a particular geographical area who may or may not share a common community goal or have sense of identity and belonging.

The UNCRPD and ADP both require that all PWDs participate and be included in their communities. Inclusion means the removal of all kinds of barriers which block PWDs from access to the mainstream. Inclusion means placing disability issues and PWDs in the mainstream activities, rather than as an after-thought or 'bolt-on.[355] Community inclusion, on the other hand, is perceived as the opportunity to live in the community and be valued for one's uniqueness and abilities like everyone else. It encompasses housing, employment, education, health status, leisure, religion, citizenship, valued social roles, peer support, self-determination, and should result in the community presence and participation of

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[351] Twinomugisha, 'A Health and Human Rights Critique', at 32; Ojok, 'Mapping the Assessment', at 24; MDAC and MHU, 'Psychiatric hospitals', at 54; WHO, 'Innovations in Deinstitutionalisation', at 17; WHO, 'Pyramid Framework', at 2; WHO, 'Mental Health Atlas 2020', at 81-83.
[352] Article 3(c) of the UNCRPD and Article 3(c) of the ADP.
[353] Kanter, *The Development of Disability*, at 74.
[354] Kamundia, 'Choice, Support and Inclusion', at 54.
[355] WHO, 'Meeting report for development of Guidelines for CBR Programmes', at 6.

PWDs similar to that of all others without a disability label.[356] Using the term 'social inclusion', Bates and Davis note that,

> Persons with disabilities have "full and fair" access to activities, social roles and relationships directly alongside non-disabled citizens. This includes the right to receive an education, live independently in the community, receive adequate and appropriate support services, and obtain accessible technology and transportation… Social inclusion also encompasses more intangible factors, such as being treated with dignity and respect, being able to form and maintain friendships and intimate relationships and generally being able to live as equals in the broader community."[357]

In addition, community participation connotes the involvement of people in all aspects of life of their communities. It entails the engagement of individuals in making decisions and taking part in matters that affect their lives in the community.[358] As Fox opines, community participation requires that the system, structures and physical environment are accessible and that people have the support they need to participate [and be included] in their communities.[359] While advocating for the decolonisation of health systems and enhancing community participation to restore trust in the health sector and leverage on indigenous ideas, Mulumba, Ruano, Perehudoff *et al*, assert that decolonizing community participation must be premised on the recognition of each person as a valid speaking partner with a unique and valuable knowledge to contribute. Thus, respect for the inherent dignity of persons and self-determination must inform all participatory processes and strategies, and each person's expertise, experience, and input must be valued.[360]

Hence, this thesis adopts the understanding that community inclusion for PWDs entails the adoption of measures that ensure the mainstreaming of all opportunities and provision of necessary individualised support in order to promote

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[356] Illinois Department of Human Science, 'Module 5: Community Inclusion', at 4.
[357] Bates and Davis, 'Social capital, Social Inclusion and services for persons with learning disabilities', at 195-207, *cited* in Schur, Kruse and Blanck, *Sidelined or Mainstreamed*?, at 117.
[358]Burns, Haywood, Taylor *et al*, 'Community participation', at 2.
[359] Fox, 'What is Fair?', at 165.
[360] Mulumba, Ruano, Perehudoff and Oom, 'Decolonizing health governance', at 269.

inclusion, involvement and participation of all PWDs — irrespective of the nature of their disability — in all aspects of life within their communities.

3.2.2.2 The right to community inclusion

All PWDs have the right to community inclusion as enshrined in Article 19 of the UNCRPD and 14 of the ADP. PWDs deserve to be included and provided with opportunities to participate in community life on an equal basis with their non-disabled counterparts.[361] The UNCRPD Committee opines that:

> The right to be included in the community relates to the principle of full and effective inclusion and participation in society as enshrined in, among others, Article 3 (c) of the Convention. It includes living a full social life and having access to all services offered to the public and to support services offered to persons with disabilities to enable them be fully included and participate in all spheres of social life. These services can, among others, relate to housing, transport, shopping, education, employment, recreational activities and all other facilities and services offered to the public, including social media. The right also includes, having access to all measures and events of political and cultural life in the community, among others public meetings, sports events, cultural and religious festivals and any other activity in which the person with disability wishes to participate.[362]

Therefore, the right to live and be included in the community is about being able to share in those schemes that are available and utilised by people in society such as housing, markets and transport systems just like anyone else; being able to walk down the streets and to seek friends and develop relationships with others. It is the opportunity to take risks, be responsible for one's life, and in doing so, to be accorded the same, even if incomplete, safety net and protection available to other members of the community.[363] Removal of both societal and physical barriers and adopting reasonable accommodation measures to promote inclusion is paramount in

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[361]Council of Europe Commissioner of Human Rights (COECHRs), 'The Right to Persons with Disabilities to live independently and be included in the Community', at 9.

[362]UN CRPD Committee, General Comment No. 5: para 16(b); UNCRPD Guidelines on Deinstitutionalisation: para 90-92.

[363] COECHRs, 'The Rights of Persons with Disabilities to live independently and be included in the community', at 11.

order to promote inclusion of all PWDs, including PWMDs. In *Simon Bacher v Austria,* the plaintiff was born with down's syndrome. He also has autism spectrum and occasionally needs a wheelchair. A dispute arose between Bacher and his neighbour who objected to the former's family constructing a roof over the footpath to ease Bacher's access to his house and protect it from bad weather. The city authorities also failed to make an appropriate intervention in the matter claiming that they had no authority since it was a dispute between two individuals. Hence, following a complaint filed by Viktoria Bacher (Simon Bacher's sister) on his behalf alleging violations of Articles 3, 9, 14, 19, 25, 26 and 28 of the UNCRPD. The UNCRPD Committee found Austria in violation of Bacher's right to accessibility and held that,

> Accessibility is a precondition for PWDs to live independently and participate fully and equally in society in compliance with Article 9 of the Convention. Reasonable accommodation may also be adopted as a necessary and appropriate modification to ensure that PWDs will have equal access to all goods, products and services that are open and provided to the public in a manner that ensures their effective and equal access and respects their dignity.[364]

Unfortunately, in many countries, PWDs are often not provided with the accommodation measures to ease their access to the environment and other services and promote their community participation. Njoroge, Mulangira and Lang rightly note that PWDs in developing countries are subjected to systemic social exclusion and discrimination, manifested by a multiplicity of environmental, attitudinal and institutional barriers that militate against their participation within contemporary society, and they invariably do not enjoy the same economic, social and political rights as their non-disabled peers.[365] The continued practice of marginalization and institutionalisation,[366] coupled with the lack of alternative community-based care

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[364] Communication No,26/2014.

[365] Njoroge, Murangira and Lang, 'Mainstreaming the Rights of PWDs', at 129; Kanter, *The Development of Disability,* at 75 states that PWDs have systematically been denied the right to live in a home in the community in most, if not all countries of the world.

[366] WHO, 'Innovations and Deinstitutionalisation', at 16; WHO, *World Health Report*, at 50-52; MDAC and MHU, 'Psychiatric hospitals', at 54.

and support services,[367] in addition to the use of derogatory language and labels,[368] indubitably leads to social exclusion, disempowerment, and disenfranchises PWDs and more specifically PWMDs from participating and being included in their communities.[369] As held by the United States Supreme Court in *Olmstead v L.C ex rel Zimring (Olmstead),*[370]

> Institutionalization of people with disabilities who are capable of living in the community may constitute unlawful discrimination under the Americans with Disabilities Act (ADA)... Undue institutionalisation is discriminatory because it results in dissimilar treatment settings for individuals with mental disabilities vis-à-vis individuals without mental disabilities. It requires people with mental disabilities to forego life in the community and to remain confined in institutions in order to receive needed medical health treatment, unlike people without disabilities, who may receive medical treatment in the communities.

Similarly, In *Christopher Leo v Australia,* following the arrest and detention for nine years of the complainant who had psychosocial disabilities in the high security section of the Correction Centre, without due process of the law and provision of the required mental health care and treatment. The UNCRPD Committee found Australia in violation of the rights health and Article 19 of the UNCRPD due to long term institutionalisation.[371]

Historically, the right to community inclusion for PWMDs was also recognised in a number of the soft laws that preceded the UNCRPD and now the ADP.[372] For instance, the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (UN Standard Rules) called for the need for intensified efforts to achieve the full and equal enjoyment of human rights and participation in

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[367] WHO, 'Guidance to Community mental health services', at 2-3; WHO, 'Pyramid Framework', at 2; WHO, AMIS, 'Mental Health Systems in Uganda', at 11-13; MDAC and MHU, 'Psychiatric hospitals', 44; Ojok, 'Mapping and Assessment', at 24.
[368] Naggita, 'The Solution if the Problem', at 72; Kigozi, Ssebunya, Kizza, Greene *et al*, 'A Situation Analysis', at 50-54.
[369] Rosenthal and Kanter, 'The Right to community Integration', at 343.
[370] 527 US 581 (1999).
[371] Communication N0. 17/2013; Also see *Purohit & Moore v The Gambia*.
[372] Fox, 'What is Fair?', at 151.

society by PWDs. The Standard Rules enjoined States to ensure promotion of community living and inclusion.[373] Rule 26 specifically stipulated that,

> Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment and social services.

Rule 4 of the Declaration on the Rights of the Mentally Retarded stipulated that,

> Whenever possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life. The family with which he lives should receive assistance. If care in the institution becomes necessary, it should be provided in surrounding and other circumstances as close as possible to those of normal life.[374]

Similarly, the UN General Assembly Principles for the Protection of Persons with Mental Illness and Improvement of Mental Health Care (herein after 'MI Principles') in Principle 3 provides that,[375]

> Every person with a mental illness shall have the right to live and work, as far as possible, in the community.

In addition, the ICESCR was notably the first binding treaty to recognise the right to community inclusion for PWDs. Although it had no explicit substantive provision on PWDs specifically, its Committee's General Comment No. 5 recognised the right of PWDs to be provided with support services, including assistive devises,[376] as well as to be included in the community and take part in cultural life.[377] Rightly so, Rosenthal and Kanter observed that treaties like the ICESCR established a right to community inclusion for PWDs and supported the claim that institutional

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[373] Adopted by General Assembly Resolution N0.48/96 of 20th December 1993. *See*, Preamble to the rules. Also see, ICESCR Committee, General Comments No. 5 on Article 23 of the UN CRC.
[374] Adopted at the General Assembly Resolution No. 2856 (XXVI) of 20th December 1971; Declaration on the Rights of Disabled Persons, Rule 9. Adopted by General Assembly Resolution nom 3447 (XXX) of 9th December 1975.
[375] Adopted by General Assembly Resolution 46/119 of 17th December 1991.
[376] ICESCR Committee, General Comment No. 5: para 33-34.
[377] ICESCR General Comment No.5: Paragraph 36-38.

placement itself, as well as the continued confinement of people in institutions who are capable of living in the community was prohibited.[378]

The UNCRPD Committee has also called on State Parties to ensure the involvement and participation of PWDs in the deinstitutionalisation and community inclusion process.[379] Therefore, State Parties like Uganda that continue to practice institutionalisation of PWMDs and have no significant support services for PWMDs fall short of the required international and regional standards. Hence, they must adopt measures to ensure and enable community inclusion and participation of PWMDs in their communities in conformity and compliance with Article 19 of the UNCRPD and 14 of the ADP. The next section discusses the required actions.

3.3 State obligations in fulfilling the Right to Independent Living and community inclusion

As noted above, Article 19 of the UNCRPD and 14 of the ADP enjoin States to undertake measures to ensure the realisation of the right to independent living and community inclusion. These measures include:

3.3.1 To ensure PWDs exercise their choice of where and with whom to live

As already discussed, PWMDs are often institutionalised and denied the opportunity to choose their living arrangement or their own home like their non-disabled counterparts. For instance, in *Christopher Leo v Australia*, because of the long term confinement of the complainant in a high security section of a correction centre, the UNCRPD Committee found Australia in contravention of Article 19 and the right to choice of accommodation for the complainant.

It thus held that, 'while the author was housed in a facility with high-level of disability related care and subsequently relocated to a community residence, the author was never consulted on his custody and accommodation. Further that, since

[378] Rosenthal and Kanter, *The Right to Community Integration'*, at 351.
[379] UNCRPD Committee Guidelines om Deinstitutionalisation: para 34-36.

the Convention recognises the right not to be obliged to live in a particular living arrangement and that institutionalisation as a condition to receive mental health services constitutes differential treatment on the basis of disability, confining the author to live in a special institution on account of his disability also amounted to violation of Article 5.' [380]

Article 19(a) of the UNCRPD now recognises their right of PWDs to choice of a home. In support of this provision, Kanter contends that,[381]

> The specific goal of Article 19 is to afford people with disabilities the same rights to live in a home, in the community as is enjoyed by people without disabilities. People without disabilities can choose where to live, with whom to live, but people with disabilities have not been afforded the same rights throughout history, and continue to be restricted in most countries of the world.

Fox also rightly contends that Article 19 requires States to ensure that housing and social supports are structured in a way that enables independent living and community inclusion.[382] Improving conditions within institutions is not the answer. Article 19(a) makes it clear that the unjustified segregation of disabled people in institutions is in itself a human rights violation. By freely choosing where and with whom to live, a PWD is enabled to exercise their legal capacity which is a right protected under Article 12 of the UNCRPD and Article 7 of the ADP.[383] Hence, even PWMDs must be supported to freely exercise their free will and preference regarding their choice of a place of residence or home. The UNCRPD Committee affirms that,

> Access to housing means having the option to live in the community on an equal basis with others. Article 19 is not properly implemented if housing is only provided in specifically designed areas and arranged in a way that persons with disabilities have to live in the same building, complex or neighbourhood. Accessible housing providing

[380] Communication N0. 17/2013.
[381] Kanter, '*The Development of Disability,*' at 64, 75.
[382] Fox, 'What is Fair? at 180.
[383] Quinn and Doyle, 'Taking the UNCRPD Seriously', *cited* by Laikind, ''The Application of Article 12', at 17.

> accommodation to persons with disabilities, whether they live alone or as a part of a family, must be available in sufficient number, within all areas of the community, to provide the right of persons with disabilities to choose and the possibility to do so. To this end, barrier-free new residential construction and the barrier-free retrofitting of existing residential structures are required.[384]

The right to adequate housing is also guaranteed in Article 28 of the UNCRPD.[385] This requires therefore, that government departs from institutionalisation and instead channels funds to provide accessible, affordable, adaptable and quality housing arrangements that suit unique needs of PWMDs, in addition to the relevant community-based mental health care and support services. In *Christopher Leo v Australia*, the Committee urged the government to allow the exercise of the right to live independently and be included in the community, and to take steps to the maximum of available resources to create community residences to replace institutionalised settings with support services.[386]

Hence, government can adopt the supported housing model which envisions not separate, segregated housing programs or institution-like settings for PWDs, but rather the integration of PWDs in typical housing in residential neighbourhoods and with access to support and services they may need.[387]

3.3.2 State obligation to provide individualised support services

Article 19(b) of the UNCRPD enjoins States to put in place support mechanisms such as personal assistants and other community support services, which promote

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[384] UNCRPD Committee, General Comment No.5, para 34; UNCRPD Committee Guidelines on Deinstitutionalisation: para 32 on State obligation to provide safe, accessible and affordable housing in the community.

[385] Article 20(1) of the ADP provides for the right to adequate standard of living which includes among others, State's provision of adequate housing to persons with disabilities. Also see, ICESR, Article 11 on the right to housing.

[386]Communication N0. 17/2013.

[387] Kanter, *The Development of Disability*, at 98.

independent living and inclusion in the community for PWDs.[388] The European Expert Group has noted that community-based support services refer to:

> The spectrum of services that enable individuals to live in the community. It encompasses mainstream services such as: housing, healthcare, education, employment, culture and leisure, which should be accessible to everyone regardless of the nature of their impairment or the required level of support. It also refers to specialised services, such as personal assistants, peer support, respite care and others.[389]

Such support initiatives, if provided, can enable access to equal opportunities for PWDs to enjoy all aspects of life on an equal basis with others.[390] To achieve this, however, States must attend to a range of elements. These include: ensuring that the champions of community living are involved in leading the change and that the needs and preferences of people are central to planning; respecting the experience and role of families; creating personalised support for each individual; focusing on achieving quality services and ensuring people can lead their own lives safely; recruiting and developing skilled personnel; engaging broad partnership in delivering change; establishing a clear plan and timeframe for creating the community support services; investing in communicating all this effectively to everyone affected including the communities to which people are moving; and supporting each person in their transition to community living.[391]

Similarly, the European Coalition for Community Living (ECCL) further notes that community-based services must be: person-centred; support family and

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[388] UNCRPD Committee, General Comment No. 1, para 17 defines 'support' as a broad term encompassing both formal and informal support arrangements of varying types and intensity; UNCRPD Committee Guidelines on Deinstitutionalisation: para 23-28 on the provision of community support to all PWDs to support independent living. Para 25 emphasizes that such support services for living independently should be available, accessible, acceptable, affordable and adaptable.

[389] EEG, 'Common European Guidelines on Transition', at 27; UNCRPD Committee Guidelines on Deinstitutionalisation: para 26 provides that Support services include personal assistance, peer support, supportive caregivers for children in family settings, crisis support, support for communication, support for mobility, the provision of assistive technology, support in securing housing and household help, and other community-based services. Support should also be available to gain access to and use mainstream services in such areas as education, employment, the justice system and health care.

[390] Article 3(e) provides for the principle of equal opportunity.

[391] EEG, 'Common European Guidelines on Transition', at 23.

community life; adopt a social model of disability; be user-led; ensure that the PWDs lives a good quality of life regardless of the impairment of disability; and expressed daily to the individuals.[392]

As demonstrated in *H.M v Sweden*,[393] where the author alleged violation of Articles 1, 2, 3, 4, 5, 9, 10, 14, 19, 20, 25, 26 and 28 of the UNCRPD by Sweden. She suffered from a chronic connective tissue disorder which led to hypermobility, severe laxation, fragile and easily damaged blood vessels, weak muscles and severe chronic neuralgia. She was unable to walk or stand for the last eight years, had difficulty sitting and lying down and was bedridden due to impairment. She was unable to take medicine due to her atypical hypersensitivity to medicines. The author could no longer leave her house or be transported to hospital or rehabilitation care because of her increased risk of injury. The destructive course of the impairment was hydrotherapy, which in her circumstances would only be practicable in an indoor pool in her house. The author's application for permission to build the pool on her private land to the relevant Orebro Local Housing Committee was rejected, and this decision was further upheld by the Administrative Court of Appeal. Hence the submission of the communication before the UNCRPD Committee. In finding Sweden in violation of the author's rights, the Committee held that

> The right not to be discriminated against in the enjoyment of the rights guaranteed under the Convention can be violated when States, without objective and reasonable justification, fail to treat differently persons whose situations are significantly different…In this case information before the Committee shows that the author's health condition is critical and access to the hydrotherapy pool at home is essential and an effective means to her health needs. Appropriate modification and adjustments would thus require a departure from the development plan, in order to allow the building of hydrotherapy pool. It is not even indicated whether the departure would impose a disproportionate or undue burden in line with reasonable accommodation measures…Further that, rejecting the author's application for a building permit has deprived her of access to

[392] ECCL, 'A Focus on Article 19', at 9.
[393] Communication No.3 /2011.

> hydrotherapy, the only option that could support her living and inclusion in the community without being confined in a highly specialised health-care institution. The Committee therefore concludes that the author's rights under Article 19(b) of the Convention has been violated.

Without the necessary individualised support to facilitate access, participation and inclusion in the community, PWMDs may still remain excluded from society even when not necessarily placed in institutions.[394] Contending that the right to independent living also includes access to the various services and support systems needed by PWDs, Hammaberg argued that:

> The core of the right to independent living is about neutralising the devastating isolation and loss of control over one's life, brought on people with disabilities because of their need for support against the background of an inaccessible society. "Neutralising" is understood as both removing the barriers to community access in housing and other domains, and providing access to individualised disability-related support on which enjoyment of the right depends for many individuals.[395]

Governments must therefore take concrete action to ensure that PWMDs are assessed and receive the appropriate and necessary individualised support to enable their inclusion and effective participate in the community.[396]

3.3.3 Provide accessible and responsive public services and facilities

Not only must public and social services be provided to PWMDs, but States must also ensure that the services are accessible and responsive to their specific needs. The UNCRPD Committee has urged State Parties to ensure that in the deinstitutionalisation plan all persons with disabilities have access to a variety of accessible, affordable and high-quality mainstream services in areas such as personal

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[394] Council of European Commissioner for Human Rights (COECHRs), 'The Rights of Persons with Disabilities', at 18.

[395]Hammerberg Thomas, 'The Right of People with Disabilities to live independently and be included in the Community', at 11, *cited* by Degener, 'Disability in the Human Rights Context', at 6.

[396] Parker, 'An Overview of Article 19 of the UNCRPD', *in* ECCL, 'Focusing on Article 19', at 23; UNCRPD Committee, General Comment No.5, para. 60 provides that disability support services must be provided without exclusion of PWDs for any reason.

mobility, accessibility, communication, health care, family life, an adequate standard of living, inclusive education, participation in political and public life, housing, social protection, and participation in cultural and community life, leisure, recreation and sport.[397]

Due to marginalisation, stigmatisation and exclusion, PWMDs are often impeded when attempting to access public services. Frequently, the public amenities have no reasonable accommodation measures to respond to the unique needs of PWDs. Yet, the UN ECOSOC notes that:

> The 2030 Agenda for Sustainable Development highlights the importance of leaving no one behind. Yet, due to inaccessible physical and virtual environment, inaccessible communication devices and transportation, persons with disabilities often cannot fully enjoy the opportunities and services that are available to all. Forms of transportation without ramps, schools, hospitals and workplaces only accessible by stairs, and websites which cannot be read by assistive devices prevent persons with disabilities to fully participate in society, access information, health services and education or obtain a job. Accessibility is not merely a fundamental right for persons with disabilities; it is also conducive for inclusive and sustainable development as it allows person with disabilities to become active and productive participants in society. Accessibility is therefore key to empowering persons with disabilities to live independently, be integrated in their community; and to access basic information. In essence, accessibility acts as the medium and facilitator for the full integration of all persons in society; regardless of disability.[398]

However, State failure to ensure and enhance access to public amenities amounts to discrimination against PWDs contrary to Article 5 of the UNCRPD.[399] Article 19(c) of the UNCRPD and 14(2g) of the ADP enjoin States to ensure that public services and facilities are responsive to the unique needs of PWDs and equally accessible and enjoyed by PWDs on an equal basis with others.[400] In

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[397] UNCRPD Committee Guidelines on Deinstitutionalisation: para 90-92.
[398] UN Department of Economic and Social Affairs, 'Global Status Report on Disability and Development', at 51.
[399] Kamundia, 'Choice, Support and Inclusion', at 48.
[400] Accessibility was also advocated for in the World Programme of Action Concerning Disabled Persons (1983) and the UN Standard Rules on the Equalisation of Opportunities for Persons with

addition, Article 9 of the UNCRPD requires that States undertake measures to ensure that PWDs access, on an equal basis with others, all available public services and facilities.[401] Both State and non-State actors are obliged to adopt reasonable accommodation measures to ensure PWDs access and enjoy the public services and facilities.[402]

Access to social amenities and the physical environment is an integral aspect of independent living and community inclusion for PWDs. As demonstrated in *Ruben Calleja Loma and Alejandro Calleja Lucas v Spain*,[403] where the author who had down syndrome was moved from a mainstream school to a Special Education Centre by the Education authorities after his support from special education assistant was terminated. He also faced neglect and abuse from the teachers on grounds of his disability. The parents filed this communication claiming that the Education authorities' action amounted to violation of Ruben's rights to inclusive education in mainstream school guaranteed under Article 24 of the Convention. In considering the communication, the Committee noted inter alia that,

> No reasonable accommodation measures possible were taken to enable the author to study in a mainstream educational establishment…It states that, inclusion involves a process of systemic reform embodying changes and modifications in content, teaching methods, approaches, structures and strategies in education to overcome barriers with a vision serving to provide all students of the relevant age range with an equitable and participatory learning experience and the environment that best corresponds to their requirements and preferences...The right to non-discrimination includes the right not to be segregated and to be provided with reasonable accommodation…Hence, the Committee considers that the administrative decision to enrol Rubén in a special education centre

Disabilities (1993). Also see, UNCRPD Committee, General Comment No. 2 (2014) on Accessibility and Article 15 of the ADP.

[401] Also see, Article 15 of the ADP on accessibility.

[402]UNCRPD Committee, General Comment No. 5, Part 11: para 32. Also see, Article 2 which defines reasonable accommodation to mean and appropriate modifications and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

[403] Communication No.41/2017.

> without taking into account the opinion of his parents, without effectively exploring the possibility of making reasonable accommodations that could have allowed him to remain in the mainstream education system, without giving any weight to the reports of the clinical psychologist and the special education assistant, and without taking into account the authors' allegations regarding acts of discrimination and abuse suffered by Rubén in the mainstream school, constitutes a violation of his rights under article 24 of the Convention read alone and in conjunction with article 4.

The decision confirms that State parties are obliged to undertake all necessary measures to ensure provision of public services to all its citizens including PWDs in responsive to their special needs to promote inclusion. The UNCRPD Committee explains that the lack of available, affordable, accessible and adaptable services and facilities such as transport, health care, schools, public spaces, goods and services is part of the lacuna in realising the right to independent living and community inclusion.[404] It should be noted that access to public services also promotes the right to an adequate standard of living guaranteed under Article 28 of the UNCRPD and Article 20 of the ADP. Inaccessibility of social amenities for PWMDs perpetuates their institutionalisation and seclusion from society.[405] It is therefore imperative that all services should be accessible and responsive to all PWDs, including PWMDs, to enhance their inclusion in the communities and combat institutionalisation.

Notably, the realisation of the right to independent living and community inclusion cannot be achieved in isolation of the fulfilment of several other complementing rights. The next section discusses the interconnectivity and nexus between the right to independent living and community inclusion with various other rights guaranteed in the UNCRPD and ADP.

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[404] UN Committee, General Comment No.5, para 15(h); Fox, 'What is Fair?', at 176.
[405] Rosenthal and Kanter, 'The Right to Community Integration', at 343.

3.4 The Interconnectivity of the right to independent living and community inclusion with other rights in the UNCRPD and ADP

Article 19 of the UNCRPD encompasses both civil and political rights, as well as economic, social and cultural rights.[406] Hence, upholding the principles of the interconnectedness, indivisibility, universality, interrelatedness and interdependence of all rights.[407] Clearly, the effective realisation of the rights enshrined in Article 19 of the UNCRPD and Article 14 of the ADP calls for the comprehensive implementation of a number of other rights too.[408] This section teases out some of the rights that intersect with Article 19 of the UNCRPD and Article 14 of the ADP and other international and regional instruments.

3.4.1. Equality and Non-discrimination

As noted earlier, PWMDs often face various forms of stigma, isolation and discrimination in their communities.[409] Both the UNCRPD and the ADP guarantee the right to equality and non-discrimination of all PWDs.[410] This right is also guaranteed under other international conventions that preceded the UNCRPD and also equally apply to PWDs.[411] Flynn observes that the idea of equality is a fundamental principal running through the core of international human rights norms. It reinforces the notion that people with disabilities are equally entitled to the protection of rights like all other individuals.[412]

Equality must be understood not merely to be formal equality, but as substantive equality. Formal equality looks at the consistent treatment of everyone. Substantive equality, however, focuses on taking positive steps or adjustments to compensate for

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[406] Alston and Quinn, 'The Nature and Scope', at 159-160.
[407] Kamundia, 'Choice, Support and Inclusion', at 58; UNCRPD Committee, General Comment No.5, Part 1V: para 70-97.
[408] ECCL, 'Focusing on Article 19', at 7.
[409] ICESCR Committee, General Comment No. 5, para 15.
[410] Articles 3(b) and 5 of the UNCRPD, and Articles 3(b) and 5 of the ADP.
[411] UDHR, Article 2; ICCPR, Article 2(1); ICESCR, Article 2(2); CRC, Article 2; CEDAW, Article 2.
[412] Flynn, *From Rhetoric to Action,* at 15.

disadvantages and achieve equal outcomes.[413] For instance, in *H.M v Sweden*,[414] where Sweden's failure to adopt reasonable accommodation measures and grant the author the permission to construct the hydrotherapy pool in light of her disability was found to be a violation of Article 5 of the CRPD on non-discrimination. The UNCRPD Committee observed that, a law which is applied in a neutral manner may have discriminatory effects when the particular circumstances of the individual to whom it is applied are not taken into consideration. The right not to be discriminated against in the enjoyment of the rights guaranteed under the convention can be violated when States, without objective and reasonable justification, fail to treat differently persons whose situations are significantly different.

Discrimination on the basis of disability means any distinction, exclusion or restriction on the basis of disability that has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.[415] To ensure equality and non-discrimination, State Parties are called upon to take all steps to eliminate all forms of discrimination on the basis of disabilities.

The continued practice of institutionalisation, segregation and exclusion of PWMDs by the State or in some cases within the family, is clearly a fundamental breach of the right to equality and non-discrimination.[416] Hence, combating discrimination and ensuring equality of PWMDs on an equal basis with their non-

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[413] Barnard and Hepple, 'Substantive Equality', at 566.
[414] Communication No.3/ 2011.
[415] Article 2, UNCRPD; ICESCR Committee, General Comment No. 5, para 15. It defined disability-based discrimination as including any distinction, exclusion, restriction or preference or denial of reasonable accommodations based on disability which has the effect of nullifying or impairing the recognition, enjoyment or exercise of ESCRs.
[416] UNCRPD Preamble, paras a & h, and Articles 3(a) and 3(a) of the ADP; Flynn, *From Rhetoric to Action*, at 15; Olmstead V L.C ex rel Zimring, at 601.

disabled counterparts is key in creating equal opportunities and realising the right to inclusion of PWMDs in their communities.

3.4.2 The right to legal capacity

Legal capacity recognises a PWMD as a person before the law with legal rights to exercise. Mental capacity, on the other hand, is simply an individual's cognitive skills and decision-making abilities which varies depending on personality, environment, education, disability and other factors.[417] Legal capacity is guaranteed under Article 12 of the UNCRPD and 7 of the ADP, which states inter alia that,

1. State Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

2. State Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

3. States shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

Article 12 emphasizes the need to recognise PWDs as persons with legal personality, as rights-holders with legal agency, who must be provided with necessary support by the State to exercise their own choice, will and preference, and individual autonomy; and whose property rights must be protected. Applauding Article 12, Quinn and Doyle assert that,

> Article 12 is the most important article in the convention, and the platform for exercise of personhood (decision making ability). It is a move away from guardianship to a provision of support to exercise legal capacity. Until that recognition occurs PWDs do not have the capacity to exercise other rights in the UNCRPD.[418]

Similarly, Quinn and Stein assert that,

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[417]UNCRPD Committee, General Comment No. 1, Part 11: para 12-13.
[418] Quinn and Doyle, 'Taking the UNCRPD seriously', at 69.

> Article 12 encapsulates the revolution of ideas behind the CRPD by moving persons with disabilities from object to subject. It requires States to break down the walls between 'us' and 'them', to recognise the equal dignity and worth of persons formerly shunted aside.[419]

In a keynote address, Quinn drew a clear nexus between Article 12 and Article 19 of the UNCRPD when he opined that,

> By the paradigm shift I mean three things. I mean the shift away from treating persons with disabilities as 'objects' to be managed and cared for to honouring and respecting them as 'subjects'. I mean restoring voice, power and authority to the self over him or her. And I mean respecting this power and authority by forging pathways to independent living and participation. And as so, legal capacity to me is a continuum that connects with everything needed to enable a person flourish- a right to make decisions and have them respected, a place of one's own, a life in the community connected to friends, acquaintances and social capital, whether in public or private settings…[420]

Indeed, Article 12 presents an opportunity to achieve real equality for PWDs. Not only formal equality before the law, but also an equal recognition of PWDs as decision- makers on the same basis as people without disabilities, which has the potential to revolutionise the manner in which disability is treated in modern society.[421]

In spite of this laudable guarantee, the CRPD Committee has observed that persons with cognitive or psychosocial disabilities have been and still are, disproportionately affected by substitute decision making regimes and denial of legal capacity.[422] In a number of communications, the UNCRPD Committee has declared that the long term institutionalisation of the complainant, coupled with the inability to adopt reasonable accommodation measures to ensure that the right to

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[419] Quinn and Stein, 'Challenges of realising community living', in ECCL, 'A Focus on Article 19', at 28.
[420] Quinn, 'Rethinking Personhood', at 4.
[421] Series, Arstein-Kerslake and Kamundia, 'Legal Capacity', at 155.
[422] UNCRPD Committee, General Comment No.1, para 9.

legal capacity of the complainant is supported and recognised, and due process of the law is followed is a violation of Articles 3, 5, 12 and 19 of the Convention.[423]

The European Union Agency correctly affirms, the rights of PWDs to live independently and take decisions is not only affected by the stay in institutions, but it is also reflected in the laws and policies that uphold guardianship.[424] Article 19 emphasizes that any strategy for meaningful enjoyment of the right to independent living must allow the PWDs to be autonomous,[425] exercise their choice, will and

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[423] *Christopher Leo v Australia,* Communication No.17/2013, where the Committee held that throughout the author's detention, the judicial procedure focused on his capacity to stand trial and the State neither gave him chance to plead not guilty or challenge his charges, nor provide measures to support him in exercising his legal capacity. Recalling General Comment N0.6, the Committee finds the NT Criminal Code resulted in discriminatory treatment in violation of Article 5. Further, that States have an obligation to recognize that persons with disabilities enjoy legal capacity on an equal basis with others and must provide them with the support to exercise such capacity. Hence there was a violation of Article 12 and 13 of the Convention; *Manuwa (Kerry) Doolan v Australia*, Communication No.18/2013 in which the author who suffered from a psychosocial disability was arrested for threatening a support staff and damaging property in his temporary supported accommodation. He was then incarcerated in a Correctional Centre and subsequently in custody in prison for nearly four years and nine months. In finding Australia in violation of the Convention, the Committee noted that the national court procedure never focused on the author's mental capacity to stand trial and he was not supported to exercise his legal capacity or given the chance to plead not guilty. Hence, the criminal code resulted in discriminatory treatment of the author and violation of Article 5. In addition, no form of support or accommodation was provided to enable the author exercise legal capacity and this amounted to violation of the author's rights under Article 12 (2,3) and Article 13(1); In *Marlon James Noble v Australia,* the author with mental and intellectual disability was arrested on charges of sexual penetration of a child and three counts of indecently dealing with a child. His capacity to take plea was assessed and he was found unfit to take plea. He wasn't provided with any supports and stayed in confinement for over ten years under the Mentally Impaired Defendant Act. The Committee held that the Mentally Impaired Defendant Act was discriminatory as it applies only to persons with cognitive impairment, and provide for their indefinite detention without any finding of guilt when they are charged with criminal offences, while persons without cognitive impairment are protected from such treatment through the application of the rules of due process and fair trial. The State Party did not provide the author with the necessary support to exercise his legal capacity, and did not analyse which measures could be adopted to do so, despite the author's clear intention to take plea of not guilty. Hence the State was in violation of Article 12. Also see, *Arturo v Mexico,* Communication No.32/2015, the author was arrested on charges of stealing a vehicle and deprived of his liberty in a men's psychosocial rehabilitation centre in Mexico City and remained in detention for four years. Various efforts by his mother to the national authorities to have him released were futile. The Committee found, *inter alia,* that the author was not given necessary support to stand trial and exercise his rights to legal capacity and due process of the law. Hence the State was in violation of Article 12, among other rights.

[424] European Union Agency for Fundamental Rights (EUAFR), 'Choice and Control', at 13.

[425] Fox, 'What is Fair?, at 164 defines individual autonomy as the freedom of individuals to direct their own actions without interference from others. Further, that an autonomous person is still self-determining if he willingly takes others' needs or wishes into account, and is not coerced into taking a particular course of action; Quinn and Degener, 'Human Rights and Disability' at 15, state that

preference in determining where to stay or with whom, and what support mechanism best suits them depending on the nature of their disability.[426]

By upholding the right to equality and non-discrimination, States will pave the way for the recognition of PWDs as individuals with legal capacity and agency, individual autonomy, ability to exercise will and preferences, bearers of self-determination and decision making skills on matters that concern them.[427] Minkowitz correctly argues, that the use of support to exercise legal capacity represents a substantial departure from the earlier thinking about legal capacity, in which people were socially shamed and legally annihilated if they admitted to having a disability that had an impact upon their decision making.[428]

In recognition of these rights, States must embark on reforming laws and practices that deny the legal autonomy of all PWMDs as rights bearers on an equal basis with others, as well as adopt supported decision-making frameworks as opposed to substituted decision-making paradigms.[429]

Clearly, the right to legal capacity and independent living are intimately connected. An individual's right to self-determination are dependent on that person's contact with and participation in the broader community and opportunities to exercise choices that pertain to the various aspects of life.[430] By permitting PWMDs to live independently and be included in the community, and provide them

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autonomy entails opening up free and uncoerced space for voluntary action based on a person's conscience and freely made life choices while preserving comparable liberties for others.

[426] Also see Articles 14(2) and 7 of the ADP guarantees persons with disabilities with the right to equal recognition before and under the law and without any discrimination. It further enjoins States to undertake all legislative, programmatic and administrative measures to realise this right.

[427] UNCRPD Committee, General Comment No. 1: para 13 also distinguishes legal capacity from mental capacity. It states that legal capacity is the ability to hold rights and duties (legal standing) and to exercise the rights and duties (legal agency) and is the key to meaningful participation in society. Mental capacity, on the other hand, refers to the decision-making skills of a person, which naturally vary from one person to the other depending on many factors, including environment and social factors. See also, UNCRPD Committee, General Comment No. 5, para 27.

[428] Minkowitz, 'Abolishing Mental Health Laws', at 158; Kampf, 'Involuntary Treatment Decisions', at 140-147.

[429] Series, Kerslake and Kamundia, 'Legal Capacity', at 137-155.

[430] Flynn, 'Disability and Ageing', at 199.

with the necessary support to exercise their choice, will and preference over the various aspects of their daily life, we recognise them as persons with legal capacity to hold rights, have legal agency to exercise and enjoy those rights, and hold perpetrators accountable.

3.4.3 Prohibition of cruel, inhumane and degrading treatment

Historically, PWMDs often suffered various forms of inhumane treatment, torture and abuse during institutionalisation.[431] Even today, PWMD may suffer inhumane treatment and abuse in institutions or within the prejudiced communities.[432] Article 15 of the UNCRPD protects PWDs from being subjected to torture or cruel, inhumane and degrading treatment.[433] It also enjoins States to take legislative, administrative, judicial or other measures to prohibit and prevent cruel, inhumane and degrading treatment of PWDs on an equal basis with others.[434] Although there were earlier instruments protecting all persons against torture, Article 15 is celebrated for providing specific protection for PWDs.[435] PWMDs can use Article 15 to challenge any form of cruel and inhumane treatment they may encounter, including long-term institutionalisation, which often results in their isolation and exclusion from their families, friends and communities.[436] For instance, in *Munir al Adam v Saudi Arabia*,[437] the author claimed that as a child he suffered an injury that resulted into a partial impairment in his right ear. However, following his detention and torture by Saudi security forces he completely lost his hearing. Hence the State was in violation of his rights under Articles 4, 13, 15, 16 and 25 of the Convention. The Committee found that the State neither conducted investigation of

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[431] ECCL, 'A Focus on Article 19', at 5; WHO, 'Innovations in Deinstitutionalisation', at 16.
[432]WHO, 'Mental Health and Development', at 10-11; UNOHCHR, 'Forgotten Europeans: Forgotten Rights', at 6; Kenyan documentary: *Locked and Forgotten*; MDAC and MHU, 'Psychiatric Hospitals', at 22.
[433] Also see, Article 10 of the ADP on prohibition and prevention of torture.
[434] Article 15(2).
[435] Article 10 of the ADP guarantees the freedom of persons with disabilities from torture, cruel inhumane and degrading treatment. Also see, UDHR, Article 5; ICCPR, Article 7; UN CAT, Article 2; ACHPR, Article 5.
[436] Kanter, '*Disability Law in international*,' at 160.
[437] Communication No.38/2016

the allegations of torture in the detention facility as presented by the author and his family members, nor denied the claims. As such, the State was held to be in violation of its duty under Article 15 and 16 of the Convention relating to prohibition of torture and abuse respectively.

This thesis argues that by embarking on deinstitutionalisation and providing alternative community-based mental health care and individualised support services, PWMDs will be shielded from the various forms of cruel, inhumane and degrading treatment characteristic of institutionalisation.[438]

3.4.4 The Right to Liberty and Security of Person

Institutionalisation curtails the ability of PWMDs to freely enjoy their right to liberty and security of person guaranteed under Article 14 of the UNCRPD and Article 9 of the ADP.[439]

Article 14 of the UNCPRD provides that,

1. State Parties shall ensure that persons with disabilities, on an equal basis with others:
    a. Enjoy the right to liberty and security of persons[440]
    b. Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of disability shall in no case justify a deprivation of liberty[441]
2. State parties shall ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be

[438] *Marlon James Noble v Australia*, Communication N0.7/2012 where the complainant with a mental and intellectual disability was subjected to abuse during his long term indefinite detention for thirteen years. The UNCRPD Committee found Australia in violation of complainant's rights under Articles 5,12.13,14 and 15 of the Convention.
[439] UDHR, Article 3; ICCPR, Article 9(1); CRC, Article 37; ACHPR, Article 6.
[440] Also see, Article 9(1) of the ADP.
[441] Also see, Article 9(2a) and 9(5) of ADP.

> treated in compliance with the objectives and principles of this Convention, including by provision of reasonable accommodation.[442]

Unlike the UNCRPD, the ADP makes further stipulations that,

> State Parties shall take appropriate and effective measures to ensure that PWDs on an equal basis with others;
>
> (b) Are not forcibly confined or otherwise concealed by any person or institutions;[443]…and
>
> (c) Are protected, both within and outside the home, from all forms of exploitation, violence and abuse.[444]

Laudably, confinement or institutionalisation merely because of disability is completely outlawed. However, neither the UNCRPD nor the ADP absolutely prohibits involuntary treatment or institutionalisation of PWDs. PWMDs may be lawfully confined but with strict compliance with human rights standards and by provision of reasonable accommodations.[445] Arguably, it seems that the framers of the UNCRPD sought to strike a balance between the arguments that favoured involuntary institutionalisation to allow for treatment and safety of a PWMDs and the community while also guarding against human rights violations.[446] This balance is also manifested in *Purohit & Moore v The Gambia*, where although the African Commission observed that institutionalisation of persons with mental illness under the Lunatics Detention Act without possibility of review or appeal of the medical practitioners diagnosis does not contravene Article 6 of the ACHPRs, it was not intended to cater for situations where a person in need of medical assistance or help are institutionalised.[447] Similarly, in *Marlon James Noble v Australia*,[448] due to the long term indefinite period of detention of the complainant for over thirteen years, the

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[442] Also see, Article 9(4) of the ADP.
[443] Article 9(2b).
[444] Article 9(2c).
[445] Article 14(2) of UNCRPD; Article 9(4) of the ADP.
[446] Kanter, *The Development of Disability,* at 132.
[447] Communication No.241/2001; Christopher Leo v Australia Communication No.17/2013.
[448] Communication N0.7/2012.

Committee found Australia in violation of Article 15 of the UNCRPD. It emphasized inter alia that,

> State parties are in a special position to safeguard the rights of persons deprived of their liberty owing to the extent of the control that they exercise over those persons, including to prevent any form of treatment contrary to Article 15, and safeguard other rights enshrined in the Convention. In this context, State party authorities must pay special attention to the particular needs and possible vulnerabilities of the person concerned, including because of his or her disability…The author's indefinite detention for over thirteen years in compliance with section 10 of the Mentally Impaired Defendants Act, with evidence of abuse amounted to violation of Articles 5(1), 12(2 and 3), 13, 14(1b) and 15 of the Convention.

It is indeed plausible that some PWMDs might require institutionalisation for purposes of treatment. However, this must be done in the least restrictive environment and for the shortest period of time, in observance of human rights obligations of the State and mental health practitioners. Above all, States must prioritise provision of a comprehensive PHC system with CMHCS and support services so as to limit institutionalisation of PWMDs.

3.4.5 The right to health

In order to enjoy the right to independent living, community inclusion and participation, a person must be healthy. The UDHR recognised health as a component of the right to an adequate standard of living.[449] The ICESCR subsequently guaranteed the right to the highest attainable standard of physical and mental health.[450] Under General Comment No.14, the ICESCR Committee authoritatively explained that the right to health does not mean the right to be healthy, but rather the right to the enjoyment of a variety of facilities, goods, services

[449] Article 25.

[450] Article 12. Also see, Article 11 of Convention on the Elimination of All Forms of Racial Discrimination; Article 12 of the CEDAW; Article 24 of the CRC; Article 16 of the ACHPR; Article 18 of Maputo Protocol and Article 14 ACRWC.

and conditions that are necessary for the realisation of the highest attainable standard of physical and mental health.[451] The Committee also expounded that:

> The right to health is an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health, such as access to safe and portable water and adequate sanitation, an adequate supply of safe food, nutrition and housing…[452]

In Purohit & Moore v The Gambia, in finding the State in violation of the right to health of persons with mental illness detained in poor conditions, the African Commission observed that,

> Enjoyment of the human right to health as it is widely known is vital to all aspects of a person's life and well-being, and crucial to the realisation of all the fundamental human rights and freedoms. This right includes the right to health facilities, access to goods and services to be guaranteed to all without discrimination of any kind…As a result of their disabilities. Mental health patients should be accorded special treatment which would enable them not only attain but also sustain their optimum level of independence and performance in keeping with the standards set out in Article 18(4).[453]

Both the UNCRPD and the ADP recognise the right to the enjoyment of the highest standard of health without discrimination for all PWDs.454 Hence, to enjoy the right to independent living and community inclusion, State Parties must ensure that PWMDs are

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[451] ICESCR Committee, General Comment No. 14: para 8-9; The UNCRPD Committee have found States in violation of the right to health in a number of decisions. For instance, in *H.M v Sweden*, Communication N0.3/2011, failure to permit the author to build a hydrotherapy pool needed for her nature of disability was held to be a violation of her right to health under the Convention; in *Simon Bacher v Austria,* Communication N0. 26/2014, the refusal for the author to build a roof over his pathway amounted to violation of his right to health since his accessibility to various public services, including health facilities, would be limited; *Munir al Adam v Saudi Arabia,* Communication N0 38/2016, subjecting the author to torture by security forces while in detention, and failure to avail him with the necessary surgery he needed resulting into complete loss of his hearing, was a violation of his right to health by the State.

[452] *Ibid*, para 11; *Purohit & Moore v The Gambia*: para 80-84 on recognizing the right to health as paramount in enjoying other rights and attaining sustainable levels of independence and performance.

[453] Article 18(4) of ACHPR provides that, "The aged and disabled shall also have the right to special measures of protection in keeping with their physical and moral needs."

[454] Articles 25 and 17 respectively.

able to enjoy the available, accessible, acceptable and quality health services from within their communities.[455]

3.4.6 The right to a home and family life

Both Article 19 of the UNCRPD and Article 14 of the ADP guarantee the right of all PWDs to a home of their choice, to choose who to live with and to have the appropriate individualised support to enable PWDs participate and be included and community life. In *H.M v Sweden*, the Committee found that denial of permission to the author to construct a hydrotherapy pool amounts to a violation of her right to individualised support within her home, and would amount to her placement in a special facility excluded from her home and the society.[456] Similarly, in *Simon Bacher v Austria*, the Committee noted that the refusal for the author to construct the roof over the pathway to enable him access his home safely does not only limit access to his home , but also limits his access to social activities and to the public services that he needs for his daily life, such as education, health institutions and public services at large.[457]

Hence, providing individualized support measures and accommodations are an integral part of enabling PWDs enjoy their right to a home, family, independent living and community inclusion. The ECCL opines that the kind of relationships with family, friends and the wider community that people develop if provided the appropriate support to live in their own homes cannot be achieved in institutions, which are often placed in isolated locations, far removed from the residents' original communities.[458] Community living includes the right to enjoy family life.[459]

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[455] ICESCR Committee, General Comment No. 14: para 12; Articles 25 (c) and 17(e).

[456] Communication N0.3/2011.
[457] Communication N0.26/2014.
[458] ECCL, 'A Focus on Article 19', at 7.
[459] Inclusion International, 'Global report on Article 19', at 61; Ojok, 'Mapping and Assessment', at 39.

Article 23 of the UNCRPD and 26 of the ADP guarantee the right to family for all PWDs.[460] This right entails: the choice to marry, found a family, parenthood, access to family planning and other sexual and reproductive health services, and to have children and care for them. These rights cannot be enjoyed while confined in an institution.

In addition, the family is also a bedrock for community-based support for some PWMDs who live with their families. Unfortunately, in some cases, PWMDs may be institutionalised with no caregiver or family support,[461] abandoned or neglected, and homeless and in dire need of government intervention.[462] The family plays a fundamental role in the care, protection, provision of basic needs, including purchase of medicines and provision of accommodation, to PWMDs.[463] Findings from Ojok, Kamundia and Verity, Turiho, Mutamba *et al* study reveal that in most cases family members are often critical sources of security and support to PWMDs especially in the absence of community-based support.[464] The critical role the family plays in supporting a family member with disabilities is unequivocal and the need for support for families has been recognised by the UNCRPD Committee, which stated that:

> States Parties should provide adequate support services to family carers so they can in turn support their child or relative to live independently in the community. This support should include respite care services, childcare services and other supportive parenting services. Financial support is also crucial for family carers, who often

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[460] ADP Preamble recognises that families, guardians' caregivers and communities play essential roles in the lives of persons with disabilities; *Ruben Calleja Loma and Alejandro Calleja Lucas v Spain.* Communication No.41/2017 the Committee found that, the placing of the author in a special school, away from his family violated his rights to live with his family and access inclusive education

[461] Verity, Turiho, Mutamba *et al*, 'Family care for PWSI', at 3-4.

[462] Ojok, 'Mapping and Assessment', at 39; MDAC and MHU, 'They do not consider me a person', at 17-19.

[463] WHO, 'Resource Book on Mental Health', at 97; Kamundia, 'Choice, Support and Inclusion', at 58-59; European Union Agency for Fundamental Rights, 'Choice and Control', at 22.

[464]Ojok, 'Mapping and Assessment', at 39; Kamundia, 'Choice, Support and Inclusion', at 58-59; Verity, Tuhiro, Mutamba *et al*', 'Family care for PSMI', at 7-8; European Union Agency for Fundamental Rights, 'Choice and Control', at 68.

> live in situations of extreme poverty without the possibility of accessing the labour market.[465]

Unfortunately, families often do not receive State support or any other form of assistance to help them cope with the challenges of caring for a PWD.[466] The vital care role provided by the family to PWDs is often unrecognised, unsupported and unpaid.[467] It is worth noting that factors such as poverty, the migration of bread-winners seeking employment in distant places, and death of potential carers has made sustained family care increasingly problematic.[468]

However, it remains preferable for PWMDs to be kept within their families as opposed to institutions if they so wish. States must ensure that families receive the necessary support to facilitate them cope with the challenges of caregiving.[469] No doubt, the call for government intervention in supporting families that have members with disabilities is therefore very pertinent for the realisation of Article 19 of the UNCRPD and 14 of the ADP.[470] However, it should not be forgotten that even for those who choose to live with their families, their autonomy, choice and control over their personal lives must be respected.

3.4.7 Right of Access to justice

Access to justice connotes a process which enables people to claim and obtain justice remedies through formal or informal institutions of justice, and in conformity with human rights standards.[471] The right to access to justice is well-defined in the

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[465]UNCRPD Committee, General Comment No.5, Part 111: paras 55, 67 and 87; Declaration on the Rights of Mentally Retarded Persons, General Assembly Resolution 2856 (XXVI) of 20 December 1971. Declaration 4 recognises the role of the family. Also see, UN General Assembly Declaration on Rights of Disabled Persons Declaration No. 9.

[466] Kamundia, 'Choice, Support and Inclusion', at 58-59.

[467] Mansell, Knapp, Beadle-Brown *et al*., 'Deinstitutionalisation and Community Living', at 236.

[468] Bartlett, 'Thinking about the Rest of the World', at 407.

[469]UNCRPD Committee, General Comment No.5, Part 111: para 68.

[470] Inclusion Europe, 'Children with Intellectual Disabilities and their families', at 42.

[471] LASPNET, 'Access to Justice,' at 18.

Kenyan case of *Okenyo Omwansa George and Another v Attorney General and 2 Others*[472] in the following terms:

> Access to justice is a broad concept that defies easy definition. It includes the enshrinement of rights in the law; awareness of and understanding of the law; easy availability of information pertinent to one's rights; equal right to the protection of those rights by the law enforcement agencies; easy access to the justice system particularly the formal adjudicatory processes; availability of physical legal infrastructure; affordability of legal services; provision of a conducive environment within the judicial system; expeditious disposal of cases and enforcement of judicial decisions without delay.

The right to access justice is guaranteed under Article 13 of UNCRPD and Article 13 of ADP.[473] The Committee has in numerous cases found State Parties in brief of the obligation to provide reasonable accommodation measure and requisite support to ensure access to justice for PWDs. In *Christopher Leo v Australia*, the Committee found that by failing to provide the author with the relevant support to enable him exercise his legal a capacity and enjoy due process of the law, the State was in violation of the author's rights under Article 13.

Again, in *Munir al Adam v Saudi Arabia*, where the author alleged that he was subjected to torture by security forces and forced to confess, and his request for a lawyer was denied or ignored, the Committee stated that State Parties have the duty to ensure effective access to justice for PWDs on an equal basis with others including procedural and age-appropriate accommodations, in order to facilitate their effective role as direct or indirect participants. This entails respect of all components of the right to fair trial, including the right to be represented and not to be submitted to any direct or indirect physical or undue psychological pressure from investigating

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[472] (2012) KLR at 19/ Petition No.358 of 2011.

[473] Article 8 of UDHR provides that everyone has a right to an effective remedy by competent national tribunals for acts violating the fundamental rights granted to him/her by the constitution or by law; Article 14 and 26 of the ICCPR; Article 26 of ACHPR; Article 8 of Maputo Protocol; Article 16 of ACRWC.

authorities. By failing on this obligation, the State was in breach of Article 13 of the Convention.

Therefore, the access to justice sector must be responsive to the needs of PWDs for meaningful enforcement of all their rights once violated.

In summary, suffice to note that the rights discussed above are not the only ones pertinent to the realisation of Article 19 of UNCRPD and Article 14 of the ADP. Others include: the right to: employment,[474] education,[475] rehabilitation and habilitation,[476] the right to participation in political and cultural life,[477] accessibility.[478]

But for these rights to be enjoyed by PWMDs, States like Uganda must embark on comprehensive deinstitutionalisation processes, and provision of CMHCS embedded within an effective Primary Health Care (PHC) system in the country.

3.5 The Role of Primary Health Care (PHC) in bolstering access to CMHCS services in Uganda

Primary Health Care (PHC) is a critical component for promoting universal health coverage for all. Universal Health Coverage (UHC) refers to a health system where all people have access to the health services they need, when and where they need them, without financial hardship. It includes the full range of essential health

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[474] Article 27 of UNCRPD and Article 19 of ADP; *Marie-Louis Jungelin v Sweden*, Communication N0.5/ 2011, also in *J.M v Spain, Communication No. 37/2016* in both cases the Committee held that failure to provide reasonable accomodation measures and/or adjustments for the authors in light of their disability amounted to discrimination and exclusion from employment and violation of the right.

[475] Article 24 of UNCRPD and Article 16 of ADP; *Ruben Calleja Loma and Alejandro Calleja Lucas v Spain.* Communication No.41/2017The Committee found Spain to be in violation of the author's right to inclusive education by placing him in special school despite the objection from his family, and failure to provide him with the special assistance support.

[476] Article 26 of UNCRPD and Article 18 of ADP; *H.M v Sweden*, State violated Article 26 by not addressing the specific circumstances of her case and her particular disability related need for a hydrotherapy pool.

[477] Articles 29 and 30 of UNCRPD, and Articles 21 and 25 of ADP.

[478] Article 9 of UNCRPD, Article 3 (c) on full and effective participation in society and 3 (f) on accessibility and Article 15 of the ADP; *Simon Bacher v Austria*, Communication No. 26/2014.

services, from health promotion to prevention, treatment, rehabilitation, and palliative care.[479] Access to health care services for all remains a global challenge. At the Alma-Ata conference, 1978 in order to address the existing gross inequality in the health status of the people in both the developing and developed, Governments adopted the Alma-Ata Declaration, 1978 in which governments acknowledged their obligation in securing health of all citizens through the provision of PHC.[480] The Declaration emphasized that,

> Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process.[481]

The Declaration elucidates on the different tenets of PHC system which are relevant in promoting CBMHC include among others:

- Addresses the main health problems in the community, providing promotive, preventive, curative and rehabilitative services accordingly;
- Requires and promotes maximum community and individual self-reliance and participation in the planning, organization, operation and control of primary health care, making fullest use of local, national and other available

[479] WHO, 'Universal Health Coverage'. Available at https://www.who.int/health-topics/universal-health-coverage#tab=tab_1. (Accessed 23rd November,2022).
[480]WHO Declaration of Alma Ata, Adopted at the International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978. Available at https://cdn.who.int/media/docs/default-source/documents/almaata-declaration-en.pdf?sfvrsn=7b3c2167_2. (Accessed on 21st November, 2022)
[481]*Ibid,* Part VI.

resources; and to this end develops through appropriate education the ability of communities to participate;

- Should be sustained by integrated, functional and mutually supportive referral systems, leading to the progressive improvement of comprehensive health care for all, and giving priority to those most in need;
- Relies, at local and referral levels, on health workers, including physicians, nurses, midwives, auxiliaries and community workers as applicable, as well as traditional practitioners as needed, suitably trained socially and technically to work as a health team and to respond to the expressed health needs of the community.[482]

While discussing the negative ramifications of the 1970s global economic depression and the impact of the World Bank (WB) and International Monetary Fund (IMF) Structural Adjustment Programmes (SAP) that resulted into historical transformations in the health sector in developing countries like Uganda, Tashobya and Ogwang aver that the adoption of the Alma-Ata Declaration and innovation on PHC, which emphasized a paradigm shift from hospital-based care to provision of community health services, was a timely intervention in addressing inequities and inequalities in the health service structure and development.[483] Besides, strengthening PHC systems is commended for ensuring effective delivery of accessible, well-coordinated, comprehensive and high quality health care even during a crisis.[484] Hence, the Alma-Ata Declaration was and still remains a critical instrument in strengthening the advocacy for the right to health rights, and universal access to health services for all.

Building on the Alma-Ata Declaration, governments recently adopted the Declaration of Astana, 2018.[485] In the preamble of the Declaration of Astana,

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[482] *Ibid*, Part VII.
[483] Tashobya and Ogwang, 'Primary Health Care and Health Sector Reforms in Uganda', at 1.
[484] Bell, Kim, Bitton, Makumbi *et al*, 'Health Facility Management and Primary Health Care performance in Uganda', at 2.
[485] WHO: Declaration of Astana, adopted at the Global Conference on Primary Health Care: From Alma-Ata towards Universal Health Coverage and the Sustainable Development Goals. Conference

governments reaffirm their commitment under the Alma-Ata Declaration and the 2030 Agenda for Sustainable Development in pursuit for health for All. Governments envision a PHC and health services that are of high quality, safe, comprehensive, integrated, accessible, available and affordable for everyone and everywhere, provided with compassion, respect and dignity by health professionals who are well-trained, skilled, motivated and committed. Furthermore, governments commit to providing enabling and health-conducive environments in which individuals and communities are empowered and engaged in maintaining and enhancing their health and well-being.[486] In the Declaration, governments confirm that,

> Strengthening primary health care (PHC) is the most inclusive, effective and efficient approach to enhance people's physical and mental health, as well as social well-being, and that PHC is a cornerstone of a sustainable health system for universal health coverage (UHC) and health-related Sustainable Development Goals.[487]

Further, governments eloquently reiterated their commitment to build sustainable PHC systems that,

> PHC will be implemented in accordance with national legislation, contexts and priorities. We will strengthen health systems by investing in PHC. We will enhance capacity and infrastructure for primary care – the first contact with health services – prioritizing essential public health functions. We will prioritize disease prevention and health promotion and will aim to meet all people's health needs across the life course through comprehensive preventive, promotive, curative, rehabilitative services and palliative care. PHC will provide a comprehensive range of services and care, including but not limited to vaccination; screenings; prevention, control and management of non-communicable and communicable diseases; care and services that promote, maintain and improve maternal, newborn, child and adolescent health; and mental health and sexual and reproductive health. PHC will also be accessible, equitable, safe, of high quality,

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held on 25th-26th October, 2018 at Astana, Kazakhstan. Available at https://www.who.int/docs/default-source/primary-health/declaration/gcphc-declaration.pdf. (Accessed on 22nd November 2022).

[486] *Ibid*, Preamble.

[487] *Ibid,* Preamble 11.

> comprehensive, efficient, acceptable, available and affordable, and will deliver continuous, integrated services that are people-centred and gender-sensitive. We will strive to avoid fragmentation and ensure a functional referral system between primary and other levels of care. We will benefit from sustainable PHC that enhances health systems' resilience to prevent, detect and respond to infectious diseases and outbreaks.[488]

Furthermore, in the Astana Declaration 2018, governments acknowledge that successful implementation of PHC will require various interventions. These include: knowledge and capacity building; increased and well remunerated and skilled human resource for health care; leveraging on technology; adequate financing of the PHC sector; empowering individuals and communities, and align stakeholder support to national policies, strategies and plans.[489]

Undoubtedly, there is a nexus between provision of effective and comprehensive PHC system and enhancing access to CBMHCs for PWMDs. It is imperative therefore, for a country like Uganda to comply with the commitments made in both the Alma-Ata, 1978 and Astana, 2018 declarations, as well as with the WHO Six Health System Building Blocks, which encompasses: Leadership and governance; Service Delivery; Health System Financing; Health workforce; Medical products, vaccines and technologies; and Health Information Systems.[490] Applauding the WHO Building Block Framework, Manyazewal rightly asserts that strengthening the health system means improving these six health system building blocks and managing their interaction in ways that achieve more equitable and sustained

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[488] *Ibid*, Part V.
[489] Ibid.
[490] WHO, 'National Health Planning Tools: Health System Building Blocks'. (2010). Available at https://extranet.who.int/nhptool/BuildingBlock.aspx. (Accessed on 25th November, 2022); WHO, 'Monitoring The Building Blocks of Health Systems: A Handbook of Indicators and their Measurement Strategies', (2010) at 4. Available at https://apps.who.int/iris/bitstream/handle/10665/258734/9789241564052-eng.pdf. (Accessed on 25th November, 2022).

improvement across health services and health outcomes which require technical and political knowledge and action.[491]

In Uganda, PHC are provided by both public and private institutions, and it is the first point of contact with the health system for the majority of the population. Therefore, its effectiveness, efficiency and response is directly related to the level of health of the population.[492] The PHC services are delivered through a number of frameworks including the National Minimum Healthcare Package.[493] Suffice to note, that National Minimum Healthcare Package recognizes the need for government to provide primary mental health programmes and services to address the increasing levels of mental illness in the country.[494] This is commendable since it paves way for the provision of CMHCS.

The current health care service structure in Uganda comprises the Village Health Team (VHT)/ Health Centre 1 at the community level,[495] followed by Health Centre

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[491]Tsegahun Manyazewal, 'Using the World Health Organisation Health System building blocks through survey of healthcare professionals to determine the performance of public health care facilities.' Manyazewal Achieves of Public Health (2017), at 2. Manyazewal also explains that, *good service* deliveries are those which deliver effective, safe, quality personnel and non-personal health interventions to those that need them where, and when needed, with minimum waste of resources. A well performing *health workforce* is one that works in responsive ways, fair and efficient to achieve the best health outcomes possible given the available resources and circumstances. A well-functioning *health information systems* one that ensures production, analysis, dissemination and use of reliable and timely information on health determinants, health system performance and health status. A well-functioning health system ensures equitable access to essential *medical products, vaccines and technologies* of assured quality, safety, efficiency and cost effectiveness, with scientifically sound and cost-effective use. A *good health financing* system raises adequate funds for health, in ways that ensure people can use needed services and are protected from financial catastrophe or impoverishment associated with having to pay for them. *And Leadership and governance* involves ensuring the existence of policy frameworks combined with effective oversight, coalition building, regulation, attention to system designs and accountability. Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5651704/pdf/13690_2017_Article_221.pdf. (Accessed on 23rd November 2022).

[492] WHO and Alliance for Health, Policy and Systems Research, 'Primary Health Care Systems (PRIMASYS): Case Study from Uganda', (2017) at 8. The report reveals that government provides 66% of the health service delivery outputs.

[493] As detailed in the National Health Policy 1, 1999; National Health Policy 11, 2010; National Development Plans 1, 2, 3.

[494] National Health Policy, 1999 at 11.

[495] VHTs or Community health workers are currently being transformed into a model of community health extension workers under the MoH. Provide community based preventive and promotive health services.

II at the Parish and Sub-County level,[496] the Health Centre 111 at the County level,[497] the Health Centre 1V/ Referral facilities/ Hospitals at District or Municipal level,[498] the Regional Referral Hospitals at the Regional level,[499] the National Referral Hospitals,[500] and then the Ministry of Health[501] in that order. The structure is illustrated in the figure below.[502]

[496]Provide preventive, promotive and outpatient services, antenatal care and emergency deliveries.
[497] In addition to services of Health Centre 11, maternity, inpatient and laboratory services.
[498] In addition to services of Health Centre 111, in patient services, general surgery, emergency services and blood transfusion.
[499] In addition to services offered at the general hospital, specialist services in psychiatry, ear, nose and throat, ophthalmology, dentistry, intensive care, radiology, pathology, higher level surgical and medical services.
[500] In addition to services offered at the regional referral hospital, super specialist services.
[501] The Ministry OF Health is the administrative head of the health systems governing both public and private institutions. It also manages and supervises activities at national, regional and district headquarters.
[502] Illustration adopted from Ministry of Health, Uganda as cited by Jordanwood, Tapley, Angellah Nakyanzi, Anooj Pattnaik, and Nirmala Ravishankar. Uganda Report 1, '*How Primary Health Care Services are Financed in Uganda: A Review of the Purchasing Landscape'*. Washington, DC: ThinkWell, (2020) at 10; WHO and Alliance for Health, Policy and Systems Research, 'Primary Health Care Systems (PRIMASYS): Case Study from Uganda', (2017) at 12; Ssebunya, Nsereko, Ndyanabangi *et al*, 'Stakeholder's perceptions of help seeking behaviour', at 2; Kigozi, Ssebunya, Kizza, Green *et al*, 'A Situation Analysis', at 13.
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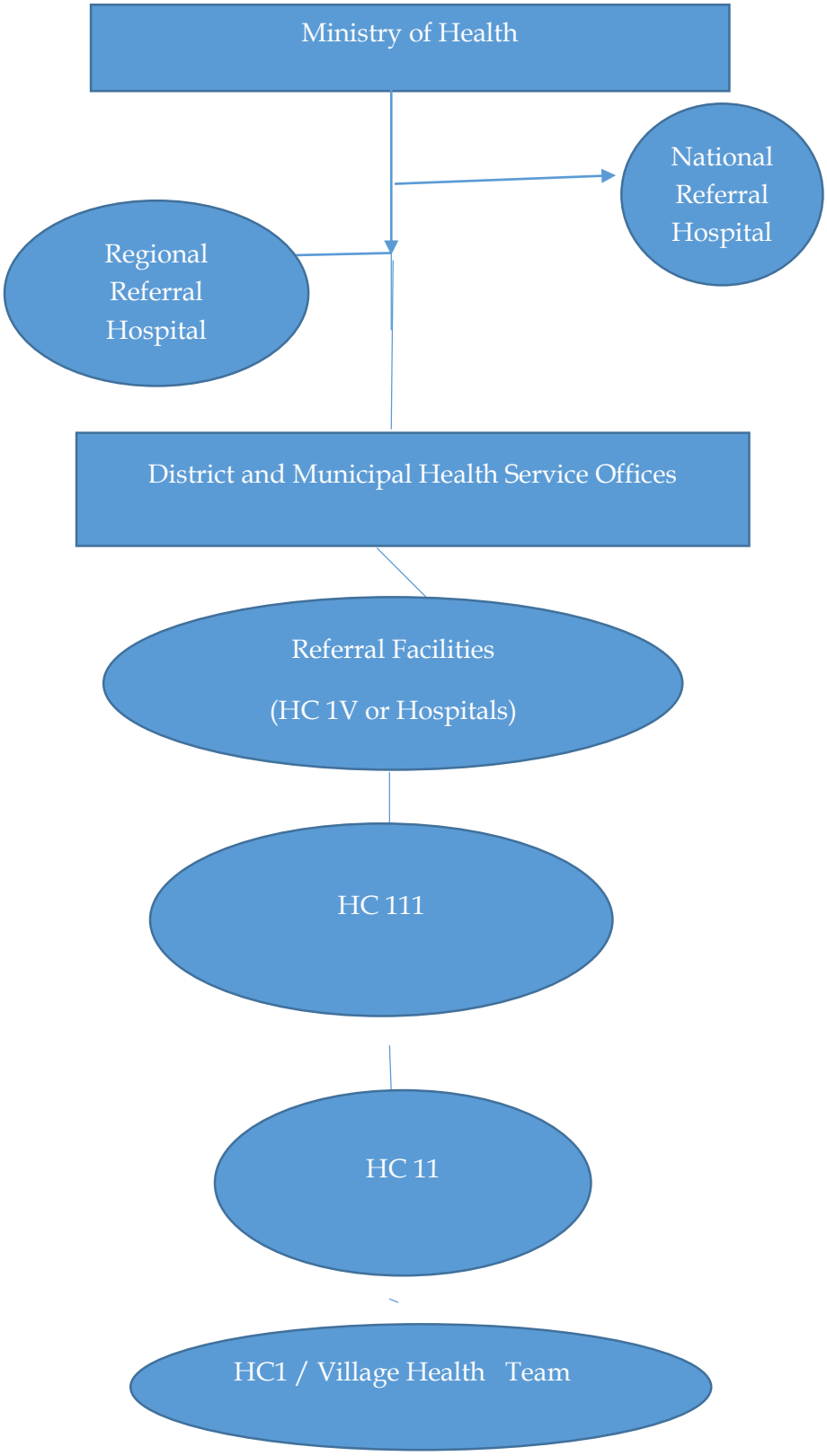
The current health care service structure in Uganda



WHO *et al* also reveals that the creation of Health Sub-Districts—that is, HC1, 11 and 111 — in 1999 was aimed at enhancing the effectiveness and efficacy of planning, provision and monitoring of health services at levels nearest to the population.[503] No wonder, in *CEHURD, Perez Mwase & Others v Buyende District Local Government and the Attorney General,* the court declared that the government's failure to provide access to early detection and management services for autism, and rehabilitation and habitation and supportive social services for Perez at the primary health center level was a violation of his right to health and the right to equality and non-discrimination enshrined in both the Constitution and the UNCRPD.[504]

In view of the existence of the relevant guidelines, policies, structures and court jurisprudence, the Uganda government ought to ensure adequate financing and engagement of skilled and motivated human resource at the various health facilities,[505] especially those at the grassroots, so as to enhance provision of comprehensive PHC.[506] Intensive community understanding, involvement and participation in PHC cannot be underscored,[507] as well as the enhancement of Community-based primary healthcare (CBPHC) which covers a range of interventions for delivering health services to hard-to-reach and under-served communities, who often represent the poorest sectors of society.[508] It is argued here that the PHC system must include provision of CBMHC services, and reach both the community, PWMDs and their families. In so doing, government will be in compliance with section 20 of the MHA, 2019 which provides that,

> A Primary Health Centre shall provide treatment for mental health illness to all patients taken to the health facility for treatment or care.

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[503]WHO and Alliance for Health, Policy and Systems Research, 'Primary Health Care Systems (PRIMASYS): Case Study from Uganda', (2017) at 13.
[504] High Court Civil Suit No. 135 of 2017.
[505] *Ibid*, at 15-17.
[506] *Ibid*, at 22 defines comprehensive services as 'the provision either directly or indirectly, of a full range of services to meet the most patients' health care needs.
[507] J.M.A Opio-Odong, 'Prospects for Primary Health Care in Uganda', Community Development Journal,' (1985) Volume 20, No.4, 273-281, at 277.
[508] Malaria Consortium, 'Community-based Primary Healthcare: The Key to Unlocking Health for All,' (2017) at 3.

It will also conform to the eloquent call by the African Commission that urges,

> State Parties to take concrete and targeted steps, while taking full advantage of their available resources, to ensure that the right to health is fully realised for the millions of people in Africa, in all its aspects without discrimination.[509]

3.6 The case for Community-based mental health care for PWMDs in Uganda

Uganda has indeed made great strides in decentralising mental health services, by integrating such services in mental health units at the regional referral hospitals.[510] As a result, formal mental health care is largely sought from the national and regional referral hospitals perceived to have adequate medication and better services.[511] Butabika Hospital is situated in the urban area (Kampala), which makes it harder for PWMDs in the rural areas to access specialized mental health services from the facility. It is estimated that over 65% of PWMDs in Uganda do not receive treatment.[512] This issue was also echoed by the State Minister of Health and some CSOs during the Parliamentary debate on the Mental Health Bill 2014, where it was noted that there is limited access to mental health care due to the limited provision of CMHCS.[513] Similarly, ISER argued that although mental health services should be integrated at all levels of the health system, they have been predominantly concentrated in urban areas and at national and regional hospitals, thus remaining out of reach of those who need them most.[514]

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[509] Purohit &Moore v The Gambia, Communication N0.241/ 2001.

[510]Ssebunya, Nsereko, Ndyanabangi *et al*, 'Stakeholder's perceptions of help seeking behaviour', at 2; Kigozi, Ssebunya, Kizza, Green *et al*, 'A Situation Analysis', at 2.

[511] *Ibid*, at 4; MDAC and MHU, 'They do not consider me a person', at 30-32; Molodynski, Cusack and Nixon, 'Desperate challenges', at 98.

[512] Mugayo, 'Cultural beliefs', at 3-4.

[513] Parliament Hansards dated 12th September 2018, at 10. The then State Minister of Health Honourable Ruth Opendi, stated to Parliament that, 'I would like to inform the honourable members that previously, the treatment was limited but now, the purpose of this Bill is to decentralise mental health services to the lower health facilities up to health centre III.'

[514]Initiative for Social Economic Rights (ISER): Analysis of the Mental Health Bill, 2014', at 6; NUDIPU, 'Consultative meeting on the Mental Health Bill, 2014', at 4; MDAC and MHU, "They don't consider me as a person", at 30.

As earlier stated, institutionalisation of PWMDs is the most dominant practice in the provision of mental health care in Uganda. According to MDAC and MHU, it is estimated that there are 937 mental health beds in the whole country,[515] yet the hospitals attend to thousands of PWMDs annually.[516] Of these bed capacities, 48% are in mental hospitals, 37% in community-based psychiatric inpatient units (regional referral hospitals), 15% in other residential facilities, and none in community residential facilities.[517] This clearly shows that the demand for mental health care supersedes the mental facilities capacity. The WHO proMind report revealed that in 2009/10 Butabika National Referral Hospital provided inpatient mental health care to at least 6,146.[518] Similarly, a study by Kigozi, Ssebunya, Kizza, Green *et al* noted that the facility has a 100% bed occupancy. Although the average number of days spent in the hospital could not be established, all patients almost spend less than one year in the hospital, except the mentally ill offenders[519], or those abandoned by their families.[520] Suffice to note also that availability of information or data regarding the length of stay in the facility remains a big challenge.[521] Basangwa discloses that the hospital is registering an increasing number of patients that are reporting for services. He observed that the bed occupancy at the facility has increased from 800-850 patients and at any one time to 900-950 admissions, and that the hospital attends to between 150 to 250 patients each day.[522] As a result, outpatient services have been intensified at the mental health facility to address the

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[515] MDAC and MHU, 'Psychiatric hospitals,' at 11; WHO proMIND, 'Mental Health in Development;' at 19; Cappo, Mutamba, and Verity, 'Belonging home,' 61.
[516] Kigozi, Ssebunya, Kizza, Green et al, 'A Situation Analysis,' at 66-68.
[517] *Ibid*, at 68; WHO, AIMS Report, 'Mental Health Systems in Uganda (2006),' at 13.
[518] WHO proMIND, 'Mental Health in Development', at 44.
[519] Kigozi, Ssebunya, Kizza, Green *et al*, 'A Situation Analysis', at 67; MDAC and MHU, 'They don't consider me as a person', at 30; WHO, 'Mental Health Atlas 2020', at 80-81. Also see, Uganda Prisons list of mentally ill offenders annexed.
[520] Verity, Turiho, Mutamba *et al*, 'Family care for PWSI', at 2-3. Note overstay and overcrowding are characteristic of Butabika Hospital. Further, that the convalescent ward is where patients are placed when they are medically stabilized and approved for discharge, but family are not ready or not willing to have them returned; Molodynski, Cusack and Nixon, 'Desperate challenges', at 98.
[521] Kigozi, Ssebunya, Kizza, Green *et al*, 'A Situation Analysis', at 66-68.
[522]URN, 'Mental Health Patients overwhelm Butabika hospital,' *The Observer News Paper*, January 13th, 2020. Interview with Dr. David Basangwa, then Executive Director.

increasing demand for mental health care services amidst the limited in-take of inpatient capacity at the facility.[523]

In terms of staffing, Butabika Hospital has a multidisciplinary team consisting of psychiatrists, clinical psychologists, psychiatric social workers, psychiatric clinical officers, psychiatric clinical nurses and occupational therapists.[524] However, Basangwa notes that the country has only 33 mental health specialists, 20 of whom are deployed in Butabika Hospital.[525] Suffice to note that inadequate staffing in the mental health care sector remains a global challenge.[526] Hence, pointing to limited access to specialized mental health personnel and services.

The table below illustrates the staffing status in the national and regional referral mental health hospitals as of 2014.[527]

Hospitals	**Psychiatrists**	**Psychiatric Clinical Officer**	**Clinical Psychologist**	**Psychiatric Social Worker**	**Psychiatric Nurse**	**Occupational Therapist**	**Mental Health Attendant**
Butabika	8	5	2	None	134	3	No information
Mulago	2	5	1	None	4	None	5
Kabale	1- on phone	6	None	None	3	None	2

[523] Kigozi, Ssebunya, Kizza, Green *et al*, 'A Situation Analysis', at 66-68.
[524] WHO proMIND, 'Mental Health in Development', at 44.
[525] URN, 'Mental Health Patients overwhelm Butabika hospital'.
[526] WHO, 'Mental Health Atlas 2020', at 61-63 at Africa reported lowest levels of workforce in the mental health care sector, with an indication of a ratio of 1.6 workers to 100,000 populations.
[527] MDAC and MHU, 'Psychiatric', at 50.

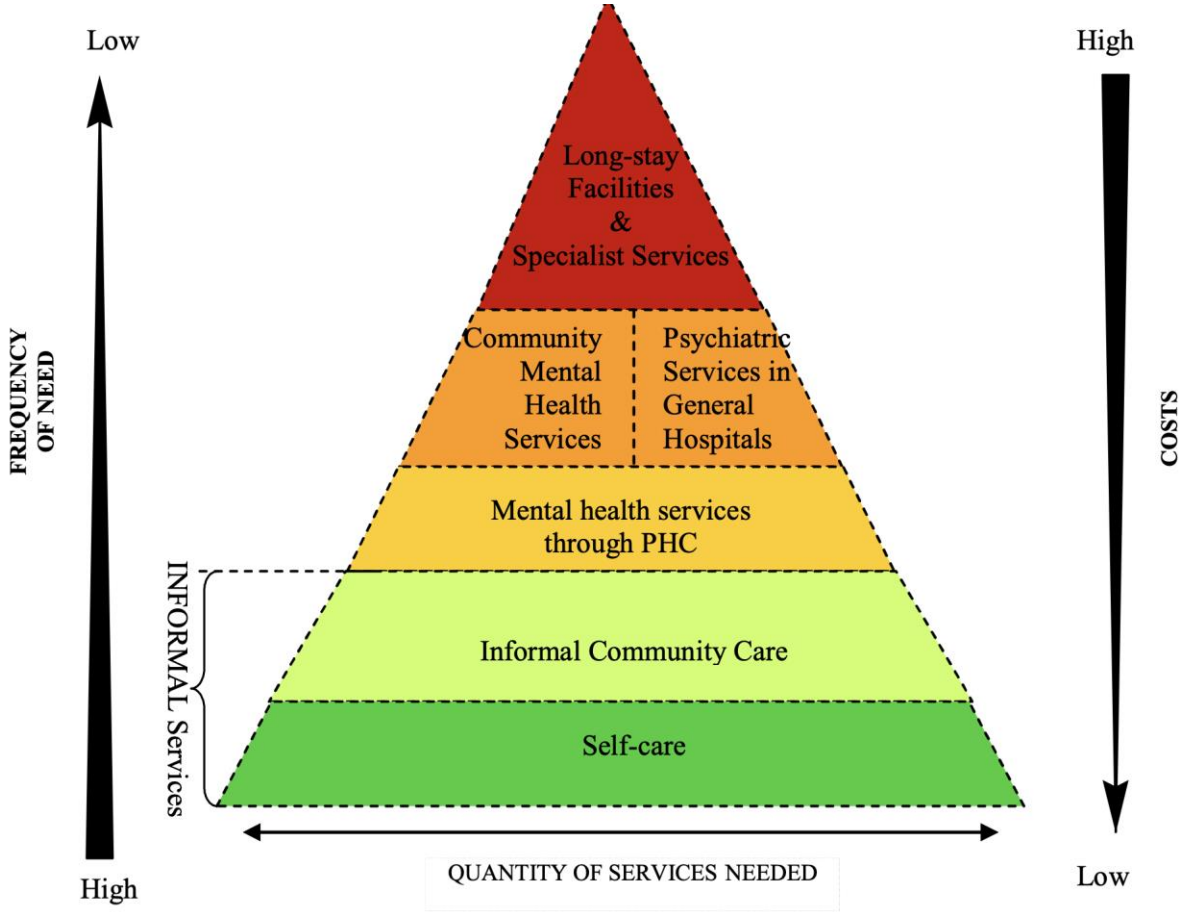
Mbarara	1	3	None	None	7	None	None
Arua	1	9	None	None	8	None	None
Gulu	1	6	None	None	3	1	6
Soroti	None	5	None	None	1	None	None
Mbale	None	6	None	1	6	None	None
Kizini	1 who visits annually	1	None	None	3	None	2

To address such gaps in mental health care, the WHO has called on States to adopt the Optimal Mix of Mental health Services: Pyramid Framework.[528] The Pyramind Framework emphasizes that:

> Countries limit mental hospitals because of the high cost, poor clinical outcomes and human rights violations; build community mental health services to ease discharge of patients from psychiatric hospitals; avoid hospitalisation of some cases and not clog the already expensive hospitals; develop mental health services in general hospitals for hospitalisation of those in acute phases of the mental condition; integrate mental health services in primary health care to allow for early identification, management of stable conditions and referral; build informal community mental health services this may include using people like traditional healers, teachers, police, spiritual leaders, village health workers, family associations to enable persons who can be managed at this level not to move higher in the pyramid, and support those recently discharged; and promote self-care where people manage their mental health themselves with the support of family and friends.[529]

[528]WHO, 'Pyramid Framework', at 1.
[529] *Ibid*, at 2-4.

The WHO: Optimal Mix of Services for Mental health: Pyramid framework is diagrammatically illustrated below.[530]



Despite the existence of Butabika, Mulago and other regional referral hospitals in the country for the provision of mental health services,[531] there is very limited or even no provision of CMHCS services.[532] Yet, CMHCS are relevant to decongest mental facilities and pave way for deinstitutionalisation, increase access to mental health care services to PWMDs within the community, reduce costs associated with visiting hospitals like transport cost, improve quality of life of PWMDs, enables caregivers save time to attend to other activities, combat community stigma and enable independent living and community inclusion for

[530] *Ibid*, at 2.
[531] Bagalaaliwo, Faridah, 'Inside Butabika: The Fear of Mental Treatment'.
[532] MDAC and MHU, 'Psychiatric Hospitals', at 44; Cappo, Mutamba, Verity, 'Belonging home', at 63; Ojok, 'Mapping and Assessment', at 24-27; Verity, Turiho, Mutamba *et al*, 'Family care for PWSI', at 2; Molodynski, Cusack and Nixon, 'Desperate challenges', at 99.

PWMDs.[533] This is exacerbated by the limited government funding to the sector, which demonstrates its lack of commitment to transform the lives of PWMDs.[534] Ojok argues that the inadequate funding, staffing and equipping of the regional referral hospitals and health centres with mental health care drugs and specialised services hinders their ability to provide CMHCS.[535] MDAC and MHU also cite limited staffing, abandonment of PWMDs by their caregivers in hospitals, the lack of super-specialised care provided by Butabika Hospital, limited budgetary allocations, over reliance of aid agencies to run community outreach activities, unaffordable and inaccessible medication in the community and lack of legal compliance as additional barriers to the provision of CMHCS.[536] The WHO confirms that the global challenge of limited funding is not only in the mental health sector, but also towards CMHCS.[537]

Community mental health practice can be seen as a multidimensional process that effectively meets a community's need for appropriate mental health care services through engaging available local, tertiary and national resources and capacities, and stimulating multiple stakeholder awareness and commitment.[538] CMHCS includes a range of services that provide care to people with mental disorders in the communities where they live and work.[539] The WHO notes that community-based mental health care services include three core components, that is:

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[533] *Ibid*, at 44; WHO, 'Pyramid Framework', at 2; Ojok, 'Mapping and Assessment', at 24; Molodynski, Cusack and Nixon, 'Desperate challenges', at 99; WHO, 'Mental Health Atlas, 2020', at 55; Hunt, 'Special Rapporteur Report on everyone to the enjoyment of highest standard of health' at 393-394 argued that CMHCS model promoted community integration of PWMDs which better supports their dignity, autonomy, equality and participation in society. It helps prevent institutionalisation…community integration is also an important strategy in breaking down stigma and discrimination against PWMDs.

[534] WHO, 'Mental Health Atlas 2017', Uganda spends less than 1% of its budget on mental health care.

[535] Ojok, 'Mapping and Assessment', at 23; Twinomugisha, 'Health and Human Rights Critique', at 44.

[536] MDAC and MHU, 'Psychiatric hospitals', at 46-48.

[537] WHO, 'Mental Health Atlas 2020', at 55-56.

[538] Basic Needs Basic Rights, 'Community Mental Health Practice', at 10.

[539] Lund and Flisher, 'A Model for CMHS in South Africa', at 1041.

community residential care; day care services; and outpatient services.[540] Thornicroft, Deb and Henderson define community based mental health care as,

> Comprising the principles and practices needed to promote mental health for a local population by: a) addressing population needs in ways that are accessible and acceptable; b) building on the goals and strengths of people who experience mental illnesses; c) promoting a wide network of supports, services and resources of adequate capacity; and d) emphasizing services that are both evidence-based and recovery-oriented.[541]

According to the WHO, the core of community-based mental health service delivery requires a multispectral approach whereby services to support individuals at different stages of the life course and, as appropriate, to facilitate their access to human rights such as employment, housing and educational opportunities, and participation in community activities, programmes and meaningful activities are available.[542] The WHO has further observed that:

> Community care is meant to address the negative aspects of institutionalisation. It is an approach which means: services which are close to home, including general hospital care for acute admissions, and long term residential facilities in the communities; interventions related to disability as well as symptoms; treatment and care specific to diagnosis and needs of each individual; a wide range of services which address the need of people with mental and behavioural disorders; services which are coordinated between mental health professionals and community agencies; ambulatory rather than static services, including which can offer home treatment; partnership with carers and meetings their needs; and legislation to support the above aspects of care.[543]

Hence, CMHCS is a multifaceted approach that requires various stakeholders including the medical personnel, community mental health teams, peer support groups, families, and the sensitized community. CMHCS is also vital in upholding respect for human dignity, and allows for the delivery of care in places close to the

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[540] *Ibid*, at 1042; WHO, AMIS Report on South Africa, at 27.
[541] Thornicroft, Deb and Henderson, 'Community mental health care worldwide', at 276.
[542] WHO, 'Mental Health Action Plan 2013-2020', at 14; The WHO, 'Guidance on Community mental health services', at 12-13.
[543] WHO, *The World Health Report*, at 50; WHO, 'Pyramid Framework', at 2- 3.

people within their communities to improve the accessibility of services and community inclusion. This thesis therefore argues that an effective CMHCS and support system also enables PWMDs enjoy the right to independent living and community inclusion.

Currently, Uganda does not have a comprehensive community-based mental health policy or programme.[544] However, the progressive MHA, 2019 laudably provides for CMHCS. It defines community-based mental health care as:

> A system of care in which the community members of a person with mental illness, in collaboration with health workers are the primary providers of the interventions to promote mental wellbeing of the person with mental illness.[545]

The MHA, 2019 further sets out in its objectives to include provision of care and treatment of PWMDs at primary health centres, and ensure that community mental health services are integrated in the treatment and care of PWMDs.[546] It places the duty on all primary health centres to provide mental treatment to all PWMDs whether they are in-patients or out-patients.[547] It further provides for District mental health focal personnel who reports to the District Health Officer, and is mandated to co-ordinate the mental health services and community mental health services in the District.[548] In its report, Parliament's Sectoral Committee on Health justified the adoption of the provisions on promoting of CMHCS, noting that it was aimed at combating institutionalisation and ensuring that mental health services are delivered without discrimination to people in their communities.[549] The Sectoral Committee's justifications were informed by the arguments made by the CSOs such

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[544] Cappo, Mutamba and Verity, 'Belonging home', at 61.
[545] *See,* Section 2. It further defines mental health services to mean the assessment, diagnosis, treatment, care, counseling or any intervention provided to promote the emotional, psychological and cognitive wellbeing of a person with mental illness.
[546] Sections 3(a) and (f) and 20.
[547] Section 20(1) and (2). Section 21 provides that a person with a mental illness shall be admitted at a primary health centre within his or her reach.
[548] Section 4(1) and (3).
[549] Parliament of Uganda, *Report of the sectoral committee on Health on the Mental Health Bill, 2014*, at 27.

as ISER, MHU and Butabika Recovery College that vehemently advocated for transition from the practice of institutionalisation of PWMDs, to promotion of independent living and community inclusion, as well as the provision of CMHCS. For instance, ISER contended that:

> Continued involuntary admission of PWMDs is a violation of Article 19 of the UNCRPD...Further that, the availability of functional facilities within the communities with access to medication, diagnostic and therapeutic equipment and the necessary and sufficient staffing ...would obviate the need for users to travel long distances seeking health services. Moreover, when people with mental illnesses are discharged from a facility, they require reintegration into the community and specialized care services, these would be provided if there are functional community based mental health care services.[550]

In agreement, Kabale in his capacity as a mental health service user, activist and on behalf of Butabika Recovery College submitted that,

> Community based mental health service is more friendly, accessible and supportive to the patients and the family/ carers. There is always a problem of drug shortage in hospitals which calls for alternative means of handling mental health issues within the community like psychotherapy, family therapy and other psychological methods within the community setting… Mental health services must start from home and even recovery is sustained at home thus the need to strengthen services at community level. Problems such as discrimination in society, lack of recognition by family members, isolation, restraint at home, churches and traditional healer's places must be addressed. The access to information by the community through awareness rising is very important when we are to change the shape of mental health care and treatment in Uganda.[551]

Attempts by mental health facilities to provide CMHCS are constrained by a number of factors including: lack of accurate data on the prevalence of mental

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[550] ISER, 'Analysis of the Mental Health Bill, 2014', at 5-6; NUDIPU, 'Consultative meeting on the Mental Health Bill, 2014', at 4. NUDIPU also contended that 'the new law should be broad enough to provide for treatment and care for persons with mental illness at all levels of the community'.
[551] Kabale, 'Submission to the Health Committee of the Parliament', at 4; MDAC and MHU, 'They don't consider me as a person', at 20-22.

health; limited human resource;[552] and inadequate financing of the health sector.[553] In addition, mental health services are largely centralised at the national and regional referral hospitals, with no national coverage or provision of community-based mental health care as provided by the MHA, 2019.[554] Yet, PWMDs are the most poor due to limited access to government economic empowerment programmes, employment, credit for equipment, land and livelihood, hence have limited income that curtails their ability to meet costs of travel to the regional or national mental health facilities.[555]

Kabale, Mundoola and Kamuhanda's testimonies illustrate the challenges faced by PWMDs in institutionalisation in Uganda. Mwase, on the other hand, could not access medical services from the inadequately resourced medical facility and encountered considerable stigma from his community until the family resorted to isolating him and restricting his liberty. Mwase's story also demonstrates the level of dependency that PWMDs with no individualised support have on their families as their primary caregivers. These testimonies justify the need for an effective PHC system infused with adequate CMHCS system.

Although the MHA, 2019 commendably guarantees the provision of community mental health services in primary health care centres, little effort has so far been employed by the government to address the shortcomings hindering the realisation of this goal.[556] It is acknowledged that the MHA, 2019 is still new, as it was passed at the time governments worldwide were grappling to recover from the devastating impact of the Covid 19 pandemic. That notwithstanding, the Uganda

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[552]Molodynki, Cusack and Nixon, 'Desperate challenges', at 98; Ojok, 'Mapping and Assessment', at 24; Twinomugisha, 'A Health and Human Rights Critique', at 14-15; MDAC and MHU, 'Psychiatric hospitals', at 44-47.

[553] Kigozi, Ssebunya, Kizza *et al*, 'Uganda's Mental Health Care Systems'; WHO, 'Mental Health Atlas 2017'; WHO, 'Mental Health Atlas 2020'; MDAC and MHU Report, 'Psychiatric Hospitals in Uganda', at 44-47.

[554] Molodynki, Cusack and Nixon, 'Desperate challenges', at 98.

[555] *Ibid*, at 99.

[556] Twinomugish, 'A Health and Human Rights Critique', at 14-15; Ojok, 'Mapping and Assessment', at 24-27.

government's perennial and perpetual non-compliance with the provisions of even its progressive laws cannot be overlooked.[557] This is exacerbated by government's underfunding of the mental health sector over the years.[558] Another blow to the sector was the recent conversion of all mental health units across the country into Covid-19 quarantine centres by the government, leaving the sector further incapacitated.[559] Hence demonstrating government's prejudice towards PWMDs and the lack of political will to adequately invest in the mental health sector. Molodynski, Cusack and Nixon rightly contend that, it is easy to see why budgets are so low if it is commonly believed by funders that the mentally ill are a 'lost cause'.[560] MDAC and MHU also correctly assert that, the transition from institutional to community-based services for people with disabilities requires both a shift of priorities and budgets. This transition is not only desirable to ensure that persons with mental health issues can remain members of their communities, but also now a requirement of governments flowing from international law.[561] These actions and omissions demonstrate government's limited commitment and interest in positively transforming the mental health sector to meet the aspirations in the MHA, 2019 and other laws.

To address the above challenges, adequate resourcing of the mental health sector must be revamped. Twinomugisha notes that in addition to funding, government needs to also embark on staff recruitment and training.[562] Governance

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[557]MDAC and MHU Report, 'Psychiatric hospitals', at 48; Ojok, 'Mapping and Assessment', at 37; Twinomugisha, 'A Health and Human Rights Critique', at 46.

[558] WHO, 'Mental Health Atlas 2017'; WHO, 'Mental Health Atlas 2020'; Twinomugisha, 'A Health and Human Rights Critique of the MHA', at 46; Mugisha, Hanlon, Ssebunya *et al*, 'Mental health users', at 2.

[559]Kamurungi, 'Mental health activists task government on restoration of services'.

[560] Molodynski, Crusack and Nixon, 'Mental Health in Uganda: Desperate challenges', at 98; Cappo, Mutamba and Verity, 'Belonging home', at 4-5; Twinomugisha, 'A Health and Human Rights Critique', at 46.

[561] MDAC and MHU, 'Psychiatric hospitals', at 44. Also see, WHO, 'Guidance on Community mental health care'; WHO, 'Innovations in Deinstitutionalisation'; WHO, 'Mental health Action Plan 2013-2020'; Murray, Ainslie, Alpough *et al*, 'The Scope', at 878-879.

[562] Twinomugisha, 'A Health and Human Rights Critique of the MHA', at 46.

challenges in the provision of primary health care must also be addressed.[563] Kopinak advocates for the adoption of a context-specific and culturally sensitive model of managing mental health in Uganda. She argues that a move away from the medical model to a model which focuses on values, resilience, health promotion and recovery will provide a better community-based mental health care system and improve lives of Ugandan individuals and the community.[564]

3.7 Conclusion

The social and human rights models of disability inform the paradigm shift from institutionalisation to the call to promote the rights of PWMDs to independent living and community inclusion as enshrined in Article 19 of the UNCRPD and now Article 14 of the ADP. It is contended here that an effective community-based mental health care programme improves the lives of those accessing services from within the community compared to the institutionalisation of PWMD.[565] It is therefore imperative that Uganda adopts a comprehensive community-based mental health services strategy. The new MHA, 2019 is the initial first step, its stipulations on CMHCS must be leveraged to actualize the provision of CMHCS services to PWMDs. Twinomugisha rightly recommends that the government should develop a Mental Health Policy and Strategic Plan to aid the implementation of the MHA. It should also develop relevant regulations to give effect to the critical provisions of the MHA. Government should take mental health seriously.[566] Short of this, the laudable MHA 2019, together with the PWD Act 2020, will be another rhetorical set of progressive laws passed to gather dust on the shelve or just 'a mere paper tiger'.

However, ensure comprehensive PHC systems with provision of CMHCS must be buttressed by provision of other community-based support services such as: personal assistants; counseling; social grants; mental health education; financial and

[563] Mugisha, Ssebunya and Kigozi, 'Governance of Primary health care', at 4-11.
[564]Kopinak, 'Mental Health in Developing Countries', at 28; Molodynki, Cusack and Nixon, 'Desperate challenges', at 99.
[565]Thornicroft, Deb and Henderson, 'Community mental health care worldwide', at 282.
[566] Twinomugisha, 'A Health and Human Rights Critique', at 46.

other support to the families as primary caregivers of PWMDs.[567] The State must ensure accessibility and availability of social services, and access to economic empowerment programmes.[568] This thesis argues that provision of CMHCS to PWMDs is a fundamental pathway for enabling Uganda to transit from institutionalisation of PWMDs to deinstitutionalisation, and to realise the right to independent living and community inclusion as guaranteed in the UNCRPD and ADP. This must be provided within the parameters of the legal regime.

The following chapter reviews Uganda's legal and policy frameworks and their conformity with international and regional standards set in various treaties, and discusses the programmatic efforts undertaken by the government to protect the rights of PWMDs in Uganda to independent living and community inclusion.

[567] ENIL, 'Barriers to Independent Living', at 21, emphasizes the importance of family support to PWDs daily life and even enabling independent living and community inclusion.
[568]Council of Europe Commission for Human Rights, 'The Right of persons with disabilities to live Independently and be included in the Community', at 11.

CHAPTER FOUR

THE INTERNATIONAL, REGIONAL AND DOMESTIC LEGAL FRAMEWORK FOR THE PROTECTION OF THE RIGHTS OF PERSONS WITH MENTAL DISABILITIES IN UGANDA

4.1 Introduction

This Chapter reviews the existing legal and policy frameworks for the protection of the rights of PWMD in Uganda and the extent to which they conform to the international and regional treaties and standards. The discussion will focus on the rights that have a nexus with the realisation of the right of PWMDs to independent living and community inclusion. Notably, at the national level, neither the PWD Act, 2020 nor the MHA, 2019 provide for the right to independent living and community inclusion. Section 4 of the PWD Act, 2020 alludes to the right to a home for PWDs. However, the broad provision in Article 35 of the Uganda Constitution, 1995 that recognises the rights of all PWDs and provides for the need to adopt measures to enable PWDs exercise their full potential, as well as the explicit domestication of the UNCRPD by section 3(2) of the PWD, Act 2020 can be leveraged.

I adopt a thematic approach to examine the relevant rights set out in the international, regional and national legal regimes and further contend that the provision of CMHCS is a measure to enable PWMDs in Uganda enjoy their rights including the right to independent living and community inclusion, and realise their full potential.

4.1 The Law and the Right to Independent Living and community inclusion

Apart from the UNCRPD, Uganda is party to several other international and regional conventions that guarantee fundamental human rights and freedoms to all people, including PWDs. These instruments include: the Universal Declaration of Human Rights (UDHR),[569] the International Covenant on Civil and Political Rights

[569] Adopted at the 3rd session on 10th December 1948, Resolution No.217.

(ICCPR),[570] the International Covenant on Economic, Social and Cultural Rights (ICESCR),[571] the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT),[572] the Convention on the Rights of the Child (CRC),[573] the African Charter on Human and Peoples' Rights (ACHPR),[574] the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women (Maputo Protocol),[575] the African Charter on the Rights and Welfare of the African Child (ACRWC),[576] and the African Youth Charter (AYC).[577] Notably, all these instruments preceded the UNCRPD, but had limited provisions specific to PWDs.[578] Although the instruments made no express mention of the rights to independent living and community inclusion for PWDs, they enjoined States to undertake measures to ensure equal access of PWDs to various aspects of society including education, employment, health care, training, sports, culture and recreation services.[579]

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[570] Adopted by the UN General Assembly on 19th December 1966 and ratified by Uganda on 21st January 1987.

[571] Adopted by the UN General Assembly on 16th December 1966 and ratified by Uganda on 21st January 1987. Note that the UDHR, ICCPR and the ICESCR are commonly referred to as the 'International Bill of Rights'.

[572] Adopted by UN General Assembly Resolution 39/46 of 10th December 1984.

[573] Adopted by UN General Assembly Resolution 44/25 of 20th November 1989 and ratified by Uganda on 17th August 1990. *See*, Article 2 on non- discrimination of children on grounds of disability, among others. Article 23 which enjoins State Parties to protect to rights of a mentally or physically disabled child to enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

[574] Adopted by the Organisation of African Unity (OAU), now African Union (AU) on 27th June 1981.

[575] Adopted by the OAU on 11th July 2003.

[576] Adopted by the OAU on 1st July 1990. *See*, Article 13 guaranteed the right to disabled child to special measures of protection in keeping with his / her physical or moral needs and under conditions which ensure his/ her dignity, promote his/her reliance and active participation in the community.

[577] Adopted by the AU on 2nd July 2006.

[578] *See*, General Comment No. 5 of the ICESCR Committee; Maputo Protocol, Article 23; and the AYC, Article 24.

[579] *See*, General Comment No.5 of the ICESCR Committee. Article 23(a) of the Maputo Protocol stipulates that State Parties undertake to ensure protection of women with disabilities and take specific measures commensurate with their physical, economic and social needs to facilitate their access to employment, professional and vocational training as well as their participation in decision making. Clause (b) enjoins State Parties to ensure the right of women with disabilities to freedom from violence including sexual violence, discrimination based on disability and the right to be treated with dignity; Article 24(1) of the AYC provides for State Parties to recognise the right of mentally and physically challenged youth to special care and to ensure that they have equal and effective access to education, training, health care services, employment, sports, physical education and cultural and recreation

At the domestic level, Article 35 of the Uganda Constitution, 1995 specifically guarantees the rights of PWDs to protection, respect and realisation of their full mental and physical potential.[580] In addition, Article 35(2) mandates the Parliament of Uganda to enact laws for the protection of the rights of PWDs.[581] Pursuant to this, Parliament has enacted various domestic laws such as: Person with Disability Act 2020,[582] Mental Health Act 2019,[583] and Children Act Cap 59 (as Amended).[584]

Specific to PWMDs, the Mental Health Act, 2019 (later analysed) introduces a number of progressive reforms in addressing the glaring gaps in the Mental Treatment Act, 1964. These reforms include: the elimination of use of derogatory language in reference to PWMDs[585]; the establishment of a Mental Health Advisory Board with supervisory powers over the management of mental health services, and quasi-judicial powers as a tribunal to receive complaints from patients regarding any form of human rights violations.[586] The Act also spells out fundamental rights of PWMDs in addition to those contained in the PWD Act 2020, the Uganda Constitution, 1995 and the UNCRPD. Suffice to acknowledge from the onset is that the celebrated PWD Act, 2020 and the MHA, 2019 are really new laws.[587] They contain more progressive provisions as compared to their predecessors. Some of the

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activities. Clause (2) enjoins State Parties to work towards eliminating any obstacles that may have negative implications for the full integration of mentally and physically challenged youth including provision of appropriate infrastructure and services to facilitate easy mobility.

[580] The Uganda Constitution, 1995 contains the Bill of Rights that spells out the entitlements of human beings. These include: Articles 20 (which provides that human rights are inherent to all human beings); Article 21 (on the right to equality and non-discrimination); Article 22 (on the right to life); Article 32 (on affirmative action for all marginalised groups), among others.

[581] Article 35(2) provides that Parliament shall enact laws appropriate for the protection of persons with disabilities.

[582] Repealing the Persons with Disability Act, 2006. Note that the Draft Persons with Disabilities Regulations 2021 are currently being developed.

[583] Repealing the Mental Health Treatment Act, 1964.

[584] Section 9 of the CA, Cap 59 places a duty on both parents and the State to ensure that children with disabilities are assessed as early as possible and offered the appropriate treatment, and afforded facilities for rehabilitation and equal opportunities in education. Also see, Children (Amendment) Act 2016.

[585] *CEHURD and Iga Daniel v The Attorney General* where the constitutional court held that the use of derogative language in reference to persons with disabilities is unconstitutional and a violation of their fundamental rights to non-discrimination.

[586] Section 14.

[587] PWD Act, 2020 repeals the PWD Act, 2006; and the MHA, 2019 repeals the MTA, 1964.

provisions (as discussed later) guarantee the protection of the rights of PWDs and also have a bearing on the need to provide CMHCS. Appraising the MHA 2019, Twinomugisha rightly notes that,

> The MHA, 2019 is a progressive legislation that significantly improves Uganda's mental health system. To a large extent, the MHA, 2019 is in tandem with the WHO Resource Book on Mental Health, Human Rights and Legislation and recognises a number of rights and freedoms enshrined in the UNCRPD, the ADP and the PWD, Act 2020. The MHA promotes the health and human rights of PWMDs and the population. However, there exist gaps in the MHA, 2019 which call for amendment of the Act [and stern government action] to ensure the protection of rights and well-being of PWMDs.[588]

So, in spite of this positive legislative development, meaningful transition in the lives of PWDs will require absolute government commitment to take all necessary steps, including providing the necessary resources and political will, to effectively implement the laws.[589] Like Twinomugisha asserts, government must take mental health seriously. It must provide the resources, recruit and train the staff, and pass the relevant policies and regulations to facilitate the effective implementation of the critical provisions of the MHA, 2019 (and related laws).[590] Short of this, the progressive laws become mere rhetoric or 'paper tigers' with no significant transformation.

The international and regional instruments, together with the progressive national laws, guarantee several rights that must be enjoyed by all PWDs, including PWMDs, as part of the human race, and are equally germane to the realization of the right to independent living and community inclusion of PWMDs. The next section entails a thematic discussion on how Uganda's various laws and policies are in

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[588] Twinomugisha, 'A Health and Human Rights Critique', at 46.
[589] Molodynki, Cusack and Nixon, 'Desperate challenges', at 99; Mugisha, Ssebunya and Kigozi, 'Governance of Primary Health Care', at 4-11; Mugisha, Hanlon, Ssebunya *et al*, 'Mental health users', at 2; WHO, 'Mental Health Atlas 2020.'
[590] Twinomugisha, 'A Health and Human Rights Critique', at 46; Ojok, 'Mapping and Assessment', at 31; MDAC and MHU, 'Psychiatric hospitals', at 48; Murray, Ainslie, Alpough *et al*, 'The Scope', at 878-879.

tandem with the norms and standards for the protection of the rights of PWMDs as expressed in international and regional legal instruments.

4.1.1 Equality and non-discrimination

The ICESCR Committee observed that the impact of disability-based discrimination has been particularly severe in the fields of education, employment, housing, transport, cultural life and access to public places and services.[591] Equality and non-discrimination is a cardinal principle under Article 3(b) of the UNCRPD.[592] The right to equality and non-discrimination of all persons is guaranteed under Article 2 of the UDHR, Article 2 of the ICCPR, Article 2 of the ICESCR and Article 2 of ACHPR.[593] In these instruments, although disability was not listed among the grounds of discrimination, it is rightly argued that it can be included in *'other status'* as mentioned in the instruments.[594] Notably, that Article 23(b) of the Maputo Protocol enjoins States to undertake measures to eliminate discrimination against women based on disability.

In Uganda, discrimination on various grounds, including disability, is explicitly prohibited under Article 21 of the country's 1995 Constitution. The PWD Act, 2020 also enjoins both the government, non-State actors and all other persons to respect and uphold the rights enshrined in both the Constitution and UNCRPD.[595] In *CEHURD, Perez Mwase & Others v Buyende District Local Government and Attorney General,* the court held that by failing to provide accessible and early detection and management of autism services at the PHC centers required by Perez, the

[591] ICESCR Committee, General Comment No. 5: para 15; UNCRPD Committee, General Comment No.6: para 3.
[592] Article 5 of both UNCRPD and ADP.
[593] ICEASR Committee, General Comment No. 5, para 15 notes that both de jure and de facto discrimination of PWDs have a long history and takes various forms including segregation and isolation achieved through imposition of physical and social barriers.
[594] Article 2 of the ACHPR.
[595] Section 3(b) of PWD Act, 2020; Also see Article 17 and 20 of Constitution.

government violated his (Perez's) right to equality and non-discrimination enshrined in both the UNCRPD and Article 21 of the Uganda Constitution.[596]

Specific to PWMDs, Section 53(1) of the MHA, 2019 clearly prohibits discrimination of any persons on grounds of mental health illness. This reform followed the Constitutional Court's pronouncement in *CEHURD & Iga Daniel v The Attorney General* where, in determining the issue as to whether section 45 of the Trial on Indictment Act Cap. 23 and its treatment of PWMDs as criminal lunatics was discriminatory, the court held that:

> Our view is that section 45(5) of the Trial on Indictment Act Cap 23 (TIA), gives different treatment to persons with mental illness/ impairments from other people without disabilities in that it imputes criminality on the person of the mentally ill/impaired who has not been adjudged a criminal. This is discriminatory. Uganda being a signatory to both the UNCRPD and the ACHPRs should have taken and ought to take steps to align section 45(5) of TIA with the Constitution and its international obligations. Our judgment is that the presumption of innocence should apply to all without discrimination. Hence the section is in contravention of the law.[597]

Also, the UNCRPD Committee has emphasized that the continued institutionalisation of PWDs as a condition to receive public sector mental health services constitutes differential treatment on the basis of disability and, as such, is discriminatory.[598]

In spite of these eloquent provisions, PWDs still face multidimensional exclusion from society which negatively impacts their quality of life and social

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[596] High Court Civil Suit No. 135 of 2017.
[597] Constitutional Petition No. 64 of 2011. Note that the Court applied the principles in *Purohit and Moore v The Gambia* in the determination of this petition.
[598] UNCRPD Committee, General Comment No. 6: para 58; UNCRPD Guidelines on Deinstitutionalisation: para 32.

integration.[599] The UFDS report also revealed that 28% of PWMDs confirmed that they had suffered discrimination.[600] Discrimination, stigmatisation and marginalisation hinders the ability of PWMDs to live independently and be included in the community.[601] This manifests in the fact that PWMDs are often impeded from accessing education, employment, economic empowerment initiatives, health services, physically or sexually assaulted, denied access to justice, to mention a few.[602] This must be tackled by the government through implementing its progressive laws, providing resources for the various sectors to execute their respective mandate to combat disability discrimination, ensuring the mainstreaming of all services to enable the inclusion of all PWDs, and deepening public awareness and sensitization on PWD rights and the obligations of the State and non-State actors. After all, the UNCRPD Committee also enjoins State Parties to address all forms of discrimination in society in order to enable PWDs live independently and be included in the community.[603]

4.1.2 Equal recognition as persons before the law

Equal recognition before the law relates to the acknowledgement of the legal capacity of all persons, as individuals before the law with equal rights and responsibility. The UNCRPD Committee notes that legal capacity includes capacity to be both a rights-holder and actor under the law.[604] It entitles a person to full protection under the legal system, with the capacity to hold and enjoy rights and duties.[605] Mental capacity refers to the decision making skill of a person, which vary from one person to another and may be different for a given person at a particular

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[599] National Planning Authority (NPA), 'National Disability Inclusive Guidelines for Uganda', at 5. Multidimensional exclusion refers to exclusion across more than one domain or dimension of disadvantage, resulting in severe negative consequences for quality of life, well-being and future life chances.
[600] UBOS, 'UFDS report', at 27.
[601] MDAC and MHU, 'They do not consider me a person', at 21-25.
[602] UBOS, 'Bridging the Gap'; MGLSD, 'Renewing Governments Commitment'; NUDIPU, 'Disability-Demands'; MDAC and MHU, 'They do not consider me a person', at 23-25.
[603] UNCRPD Committee, General Comment No. 6: para 57-60.
[604] UNCRPD Committee, General Comment No. 1, para 12.
[605] *Ibid*.

time, depending on many factors, including environmental and social factors.[606] The right to legal recognition before the law is also recognised in Articles 6 of the UDHR, 14 of the ICCPR and 3 of the ACHPR.

Previously, several Ugandan laws denied the legal capacity of PWMDs and barred them from taking part in several activities in society.[607] However, the celebrated decision by the Constitutional Court in *CEHURD & Iga Daniel v The Attorney General* also pronounced that the continued use of derogative terminology like criminal lunatic, idiot and imbecile in the law with reference to persons with mental illness / impairment amounted to cruel and inhuman treatment and a violation of the human dignity of such persons, and eroded their legal capacity and due process of the law.[608] Laudably, the MHA, 2019 now states that,

> A person with mental illness has the right to enjoy legal capacity on and equal basis with others in all aspects of life.[609]

Hence, this provision paves the way for PWMDs to exercise their legal agency and this is pertinent to enabling them to live independently and be integrated into the society on an equal basis with others.

4.1.3 Right to adequate housing

Housing is a basic human need which also determines one's quality of life.[610] The right to housing is an economic and social right protected and incorporated into the right to adequate standard of living.[611] As earlier alluded to, successful deinstitutionalisation and independent living processes requires PWMDs to have suitable available, acceptable and affordable housing options from which they can

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[606] UNCRPD Committee, General Comment No. 1, para 13.
[607] Article 80(2a) of the Constitution disqualifies a 'person of unsound mind' from being elected as a member of Parliament; the Divorce Act cap 249 under section 12 provides grounds for nullification of a marriage, one of which being where one of the parties is of 'unsound mind'; under Section 17.of the Succession Act Cap 162, persons of 'unsound minds' have no domicile of choose but acquire that of another person.
[608] Constitutional Petition No. 64 of 2011.
[609] Section 60(1).
[610] UNCRPD Committee, General Comment No. 6: para 68.
[611] Article 28 of UNCRPD; Article 11 of ICESCR; ICESCR Committee, General Comment No.5: para 34.

exercise their right to choose where, and with whom to live.[612] These can be community or village homes, smaller residential settlings, supported housing or living with their family. Regardless of the option, a PWMD must be supported to freely exercise their will and preference on the preferred living arrangement as stipulated in Articles 19(a) of the UNCRPD and 14(2a) of the ADP.

In Uganda, the right to housing is not spelt out in the Bill of Rights contained in the Constitution. However, under Objective XIV of the National Objectives and Directives Principles of State Policy (NODPSP), the State undertakes to ensure that all Ugandans have equal rights and opportunities and access to decent shelter.[613] The NODPSP are binding on the State as stipulated in Article 8A(1) of the Constitution.[614] (Notably, section 4 recognizes the PWDs right to a home and family life.)

Despite the laws in the statute books, PWMDs often face challenges in accessing adequate housing or shelter. Most households with PWDs live in thatched dwelling places with limited access to water and toilet facilities and are often overcrowded.[615] The Uganda Bureau of Statistics (UBOS) rightly observed that,

> Access to and ownership of housing and basic services available to household tells much about household welfare conditions. The living conditions therefore influence the quality of life. Staying in a quality home for many persons in Uganda pose a challenge due to affordability issues. It may even be worse for persons with disabilities because in addition to the affordability, PWDs may be required to live near caregivers and in some cases require adapted housing.[616]

Indeed, poverty, exclusion and marginalization of PWDs has also led to dire housing conditions. It is no wonder that PWDs are often limited to slum

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[612] Article 19(1a) of UNCRPD and Article 14(2a) of the ADP.
[613] Other opportunities listed include education, health services, clean and safe water, work, adequate clothing, food security and retirement benefits.
[614] *CEHURD and 2 others v The Executive Director Mulago Hospital and the Attorney General*, HCCS No. 212 of 2013; *CEHURD , Perez Mwase and 2 Others v Buyende District Local Government and Attorney General*, H.C.C.S No. 135 of 2017. In both decisions, the court reiterated the binding nature of Article 8A(1).
[615] UBOS, 'Bridging the Gap', at 36-37.
[616] *Ibid*, at 35.

dwellings, homelessness or institutionalised.[617] Hence, it is imperative that acceptable, affordable and accessible land and housing is made available by the government to PWMDs to enable independent living and community inclusion.[618]

4.1.4 Right to access the physical environment and social amenities

Access to social amenities like schools, hospitals, transport as guaranteed by Article 19(c) of the UNCRPD remains a challenge for PWMDs in Uganda. However, the right to education,[619]health[620] and an accessible physical environment, including buildings and transport services for PWDs, is guaranteed under the law.[621] Unfortunately, PWDs—and most especially PWMDs—have limited access to social amenities.[622] A report by UBOS revealed that over 9% of PWDs reported feeling humiliated or disrespected by the behaviour of medical staff while accessing health services.[623] The report also noted that 31% of PWDs had never been to school, which is more than twice that of their non-disabled counterparts of 13%.[624] Kasimbazi's research confirms that PWDs face several challenges in public and private transportation because standards for their mobility [depending on the various forms of disability] are not complied with.[625] These challenges include: the lack of information; no reasonable accommodation measures; no universal design; and cost of transport. The UNCRPD Committee, in its Concluding Observations on Uganda, decried the challenges of accessing transport for PWDs and urged government to

[617] Onoria, 'Adequate Housing', at 25.
[618] *Ibid*, at 31-37; UNCRPD Committee, General Comment No. 6: para 68 stipulates that State Parties are required to take immediate steps to provide persons with disabilities living in extreme poverty and destitution with a core minimum in terms of adequate food, clothing and housing.
[619] Article 13 of ICCPR, Article 17 of the ACHPR, Article 30 of the Constitution, and Section 6 of the PWD Act, 2020.
[620] Article 12 of ICCPR, Article 16 of the ACHPRs, and Sections 7 and 8 of the PWD Act, 2020.
[621] Sections 10 and 11 of the PWD Act, 2020.
[622] NPA, 'Disability Inclusive Guidelines', at 5.
[623] UBOS, 'UFDS Report', at 42.
[624] UBOS, 'Bridging the gap', at 23.
[625] Kasimbazi, 'Disability rights and transportation', at 30.

adopt an action plan to ensure accessibility to the physical environment and to transportation.[626]

As discussed earlier, access to social amenities is essential for independent living and community integration for PWMDs. Failure to achieve this perpetuates institutionalisation, marginalisation and exclusion of PWMDs.

4.1.5 Freedom from torture, cruel and inhumane treatment

As revealed by the MDAC and MHU report, PWMDs in the psychiatric hospitals are often subjected to cruel, inhumane and degrading treatment while in confinement. Kabale's story depicts the inhumane treatment he underwent during seclusion in a filthy room in Butabika hospital.[627] For Mudoola, the cruel treatment unfortunately culminated in to death. The UFDS report reveals that 54% of the adults with psychosocial and intellectual disabilities reported having faced some form of physical violence.[628] The UNCRPD Committee, in its Concluding Observations, also raised concern about the various forms of torture PWMDs are subjected to while in institutionalisation. It thus stated that,

> The Committee is concerned about the information on inhumane and cruel forced medical treatments, physical and chemical restraints, as well as isolation faced by persons with disabilities, particularly persons with psychosocial and intellectual disabilities, in psychiatric hospitals.[629]

However, the right to freedom from torture and inhumane treatment or degrading treatment is guaranteed in Article 5 of the UDHR, Article 7 of the ICCPR, and Article 5 of the ACHPR. Furthermore, Article 24 of the Uganda Constitution, 1995 and Section 5 of the PWD Act 2020 also prohibit cruel, inhumane and degrading treatment or punishment of any persons.[630] Specific to PWMDs, section 52

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[626] UNCRPD Committee, Concluding Observation: paras. 17 and 18.
[627] *CEHURD and Kabale Benon v The Attorney General*, Civil Suit No. 094 of 2015.
[628] UBOS, 'UFDS report', at 31; MDAC and MHU, 'They do not consider me a persons', at 21-23.
[629] UNCRPD Committee, Concluding Observation: para 29.
[630] Article 44 of the Constitution lists the right to freedom from torture, cruel and inhumane treatment among the non-derogable rights.

of the MHA, 2019 prohibits subjecting a PWMD to any form of torture or cruel, inhumane and degrading treatment or punishment.[631] The Constitutional Court in *CEHURD & Iga Daniel v The Attorney General* also found that the denial of due process of the law and reference to persons with mental illness and criminal lunatics was inhuman and degrading and amounted to a violation of Article 24 of the constitution. Similarly, *in Bushoborozi Eric v Uganda*,[632] employing judicial activism and drawing inspiration from earlier decisions like *Uganda v Tesimana Rosemary*[633] and *Uganda v Shabahuria Matia,*[634] Justice Batema held that the continued detention of Bushoborozi as a criminal lunatic for fourteen years was a violation of his right contrary to Articles 24 and 126 of the Constitution and set him free.

Although the learned justices of the court made no reference to the concepts of deinstitutionalisation and the right to independent living and community inclusion under the UNCRPD, their wise judicial reasoning and judicial activism confirm that they are awake to the fact that its unjust to keep PWMDs confined for too long without the requisite Minister's Orders or further judicial action to meet the secure their release, or placement in a mental health facility for treatment and care to meet the ends of justice. This is similar to the declarations of the UNCRPD Committee and African Commission in *Marlon James Noble v Australia, Christopher Leo v Australia, and Purohit and Moore v The Gambia* discussed above.[635]

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[631] Section 52(1) and (2).
[632]HCMC N0. 0011 OF 2015.
[633] Criminal Revision Cause No.0013 of 1999. In this case, Justice Egonda-Ntende dismissed the charge against an accused who had been kept on remand for nine years because she was mentally ill at the time of committing the crime. Court stated that, failure to prosecute on the part of the State Attorney within a period of three and half years after committal of the accused was gross inaction and oppressive conduct violating the human rights of the accused.
[634] Criminal Revision No.5 of 1999. In this case, Justice Egonda-Ntende again held that ruled that the High Court had inherent powers to prevent abuse of the process of the court by curtailing delays as may be necessary for achieving the ends of Justice. Persons with mental illness are legally entitled to an impartial and expeditious resolution of their cases and appropriate psychological assistance. Dumping them in prison for years without resolution of their cases is cruel, inhuman and degrading treatment contrary to article 24 of our Constitution.
[635] Communication N0.7/2012, Communication N0.17 /2013 and Communication No.241/2001 respectively.

It is argued here that provision of CMHCS will reduce incidences of unjustified and long-term confinement, inhumane treatment and torture of PWMDs in the course of offering treatment in health facilities or when in detention facilities.

4.1.6 Right to liberty and security of persons

This right is provided for in Article 3 of the UDHR, Article 9 of the ICCPR and Article 6 of the ACHPR. As discussed above, the UNCRPD prohibits arbitrary detention of PWDs on the basis of their disability alone.[636] In Uganda, although the 1995 Constitution guaranteed the right to personal liberty, it permits the detention of PWMDs for purposes of treatment and safety. Article 23(1)(f) stipulates inter alia that,

> No person shall be deprived of personal liberty except ... in the case of a person who is of unsound mind for purposes of care, treatment of that person or the protection of the community.[637]

This provision, together with the confinement procedure stipulated in the now repealed MTA 1964, paved way for the continued institutionalisation of PWMDs in mental health facilities. The Constitutional Court in *CEHURD & Iga Daniel v The Attorney General* also held that Article 23(f) only permits restriction of liberty for purposes of care and treatment or protection of the community. Hence, borrowing a leaf from *Purohit and Moore v The Gambia*, the court held that the process of determining where or not an accused person should be detained should be left to the court, with medical guidance and full compliance with due process, and not to the Minister who is required to act without medical guidance. The Court further stated that,

> The consequence of the current procedure is that it contains great potential for injustices as it may deprive the accused persons of personal liberty for an indefinite period of time. There is a very real risk of mentally ill persons disappearing in the criminal justice system

[636] Article 14 of the UNCRPD.
[637] Article 23(1)(f).

without proper standards being set for involuntary confinement and procedures for review.[638]

To address this anomaly, the MHA, 2019 further regulates the various modes of admission to ensure that PWMDs who need treatment from within the mental health facility are treated in the least restrictive manner and not subjected to long term institutionalization.[639] Hopefully, these safeguards will be complied with and lead to change in the management of PWMDs before the courts and in involuntary admissions in the future.

4.1.7 Right to health and Informed consent to treatment

The right of everyone to the enjoyment of the highest attainable standard of health is recognised in Article 25 of the UNCRPD. Notably, the ICESCR guarantees enjoyment of the highest attainable standard of physical and mental health.[640] Furthermore, General Comment No.5: paragraph 34 of the ICESCR Committee provides that the right to physical and mental health also implies the right to have access to, and to benefit from medical and social services, which enable PWDs to be independent, prevent further disability and support their social integration.

Although the right to health is not explicitly stated in the Bill of Rights of the Uganda Constitution, 1995, Objective XIV of the NODSP emphasizes State responsibility to ensure that all Ugandans, including PWMDS, enjoy health services.[641] Section 7 prohibits discrimination of PWDs in the provision of health

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[638] Constitutional Petition No.64 of 2011. Also see *Bushoborozi Eric v Uganda* HCMC No.0011 of 2015; *Uganda v Tesimana* HC Criminal Revision N0, 0013 of 1999. All are cases of long-term confinement of the suspected PWMDs awaiting minsters orders without further trial or due process of the law.

[639] Section 24(12) provides that involuntary admission shall be for a period not exceeding three (3) months unless the Board authorizes for an extension.

[640] Article 12; ACHPR, Article 16; Maputo Protocol, Article 14.

[641] Article 8A provides that Uganda shall be governed based on the principles of national interest and common good enshrined in the National Objectives and Directive Principles of State Policy; Article 45, which includes into the constitution rights and freedoms not specifically mentioned, provides that 'The rights, duties, declarations and guarantees relating to the fundamental and other human rights and freedoms specifically mentioned in chapter 4, shall not be regarded as excluding others not specifically mentioned. *See, CEHURD & Anors v Nakaseke District Local Administration,* Civil suit N0.111 of 2012', at 12 where court held that government has the duty to promote and protect the right to health.

services. In *CEHURD, Perez Mwase & others v Buyende District Local Government and The Attorney General*, the court in rightly finding that the government was in violation of various rights of Perez including the right to health by failing to provide early detection and management of autism services, rehabilitation and habilitation services at the Primary Health Centre and supportive social supportive social services, stated inter alia that,

> Although the right to health is not explicitly stated in the Constitution, there are multiple references in the Constitution and other enabling laws to public health which emphasize this right and the role of the State in the provision of healthcare to its citizens. Specifically, Article 8A (1), 35 and NODPSP XX of Constitution and Section 20 of the MHA. Uganda's commitment to international legal treaties and conventions also bind it, as a State to enhance, and provide quality public services and a minimum standard of universal health care. Existing constitutional guarantees, legal precedents and global commitments form a solid basis for a fundamental right to health and guarantees access to health legally binding on Uganda...the above emphasize the duty of government to ensure that its citizens have access to medical facilities, failure of which is a violation of the citizens right to health.[642]

Unlike its predecessors, the MHA, 2019 recognises the right to health as stipulated in both the UNCRPD and the Constitution, and further guarantees the right to free and informed consent to treatment of PWMDs.[643] This is also in compliance with Article 7 of the ICCPR that prohibits subjecting any person without his or her consent to any medical or scientific experimentation.

Hence, the provision of an effective PHC system and CMHCS, in addition to other existing health care services, would be an enormous stride in upholding this State obligation to not only protect the right to health, but also creation of conditions

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[642] HCSC No.135 of 2017.

[643] Sections 20(2), 42, 45 and 56. These provide for the need for consent to treatment at primary health care level during voluntary admissions, involuntary admissions, and the right to information and consent to treatment respectively.

which would assure to all medical services and medical attention in the event of sickness.[644]

4.1.8 Right to enjoy family life

The right to family and enjoyment of family life for all persons, including PWDs, is recognised in the various legal instruments.[645] At the national level, Article 31 of the Uganda Constitution, 1995 recognizes the right of any person of 18 years and above to marry and found a family and be treated equally at marriage, during marriage and at its dissolution. Section 4 of the PWD Act, 2020 also guarantees the right to enjoy family life.

As demonstrated by Komuhanda's case, long-term institutionalisation of PWMDs often leads to interference with the right to enjoy family life. The MHA, 2019 recognises the critical role that family members play in the care, admission, discharge and even seeking a remedy in the case of violation of rights of PWMDs while in the mental facility.[646]

It is imperative therefore that the right to family life is not interfered with, and families — as primary caregivers and critical in providing support during the process of independent living and community inclusion — are provided with the necessary support by the government in order to reduce the burden of caring for a member with a disability.[647]

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[644] Article 12 (2d) of the ICESCR.

[645]UDHR, Article 16; ICCPR, Article 23; ACHPR, Article 18; ICESCR Committee, General Comment No.5: para 30; UNCRPD, Article 23.

[646]Section 9 permits a relative or a concerned person to lodge a complaint before the Mental Health Advisory Board of behalf of the patient; Section 24(3) provides that involuntary admission of a patient can be made by a relative or concerned person in writing; Section 31 provides that discharge of a patient may be upon the request of a relative or a concerned person; *Arturo Medina Vela v Mexico*, Communication No. 32/2015, *Simon Bacher v Austria* Communication No.26/2014 and *Ruben Calleja Loma and Alejandro Calleja Lucas v Spain*, Communication No.41/2017 demonstrates role of the family members on caring for PWDs and enabling them secure remedy for any rights violations.

[647] UNCRPD Committee, Concluding Observation, para 48 (c); Ojok, 'Mapping and Assessment', at 39; Verity, Turiho, Mutamba *et al*, 'Family care for PWSI', at 6; Inclusion International, 'Global report on Article 19', at 25-29.

4.1.9 Participation and being included in the community

The rights of all persons to participate in all aspects of society including cultural life and recreation activities is guaranteed in various instruments.[648] The UNCRPD Committee notes that exclusion of PWDs from political or public life amounts to discrimination.[649] The Committee further calls on States to provide reasonable accommodations to individual persons with disabilities and support measures based on individual requirements of PWDs to participate in political and public life.[650] Hence, States must take measures that will promote inclusion and participation of PWMDs in their societies. These may include ensuring a barrier free environment, increasing disability rights awareness, combating prejudices and stigma in the community, providing supportive devices that meet individual need and amending any laws that perpetuate exclusion, disempowerment and marginalization of PWMDs in society.[651]

Article 35 of the Uganda Constitution, 1995 also guarantees the right of PWDs to live with dignity and realise their full potential. In *CEHURD, Perez Mwase and 2 Others v Buyende District Local Government & The Attorney General*, the court recognised the fact that due to inability to access treatment and rehabilitation services at an earlier stage, Perez was often tied to a tree, he cannot talk and is unable to do anything a normal human being can do, he is incapacitated. Hence, he cannot and has not lived with human dignity. The learned Judge held that,

> The right to human dignity is a fundamental right that the State need not overlook. I cannot also ignore the fact that whenever the State fails to provide for citizens to enjoy the rights enshrined in the Constitution, it culminates into violation of their rights... the 4th Plaintiff in this care was tied by ropes to curb him, and this in my view, was not only degrading treatment towards him, but also a violation of

[648] Article 15 of ICESCR and ICESCR Committee, General Comment No.5: paras. 36-38; Article 32(a) of the Maputo Protocol; Article 24 of AYC; Article 13 of ACRWC.
[649] UNCRPD Committee, General Comment No. 6: para 70.
[650] *Ibid*, para 70(c).
[651] Naggita, 'The Solution is the Problem', at 72-76; Kasimbazi, 'Disability and Transportation', at 43-44; NUDIPU, 'Disability Demands: 2016-2021', at 20-21.

> his right to live a decent life and realise his full mental and physical potential.

Similarly, in *Purohit & Moore v The Gambia*, the African Commission emphasized that State Parties must uphold the inherent right to human dignity of all human beings regardless of their mental capabilities or disabilities, and must be respected by all human beings.

These decisions clearly speak to the State obligation to provide all relevant medical, rehabilitative other support services to enable all PWDs, irrespective of their impairment, to live dignified and productive lives, participate in the community and realise their full potential which is the goal of Article 19 of the UNCRPD and 14 of the ADP.

4.1.10 Right to Employment

The right to work for all persons is also guaranteed in the treaties to which Uganda is party.[652] At the national level, the right to work is recognised in the Uganda Constitution, 1995[653] and the Employment Act, 2006.[654] With regard to PWDs, section 9 of the PWDs Act, 2020 prohibits discrimination in employment on grounds of disability and enjoins employers to provide reasonable accommodation measures to enable PWDs to perform their tasks. Access to employment or economic empowerment opportunity is a critical factor in combating poverty, ensuring self-reliance and promoting independent living and community inclusion for all PWDs. As Mpanga opines, employment leads to individual empowerment and transformation of one's life and that of their families and dependants. Employment offers a gateway to economic independence, personal social dignity or self-worth, and a better quality of life.[655]

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[652] Article 27 of UNCRPD; Article 19 of ADP; Article 25 of ICCPR; Articles 6 and 7 of ICESCR; Article 11 of CEDAW; Article 15 of ACHPR; Article 13 of the Maputo Protocol.
[653] Article 40 guarantees economic rights and the right of every person to practice his/ her profession, which provision also applies PWDs.
[654] Section 6 prohibits discrimination in employment on many grounds including disability.
[655] Mpanga, 'PWDs in Recruitment', at 45.

Yet, NUDIPU reveals that more than 7 out of 10 PWDs live in abject poverty with very low literacy levels.[656] NUDIPU further report that PWDs are more likely to be unemployed and earn less even when employed. It is also harder for PWDs to benefit from development processes and escape poverty due to discrimination in employment, limited access to transport, and lack of access to resources to promote self-employment and livelihood activities.[657]

The UNCRPD Committee enjoins State Parties to ensure that there is no discrimination on the grounds of disability in connection to work and employment.[658] Therefore, in light of the State obligations stipulated in the laws, government must embark on measures to promote access to employment and economic initiatives for PWDs in both public and private entities taking into consideration the varying nature of disabilities, reasonable accommodation measures and universal designs.[659]

From the above legal analysis, it can be deduced that there is certainly a fertile bed of legal and policy frameworks for the protection of the rights of PWMDs, provision of PHC system with CMHCS and the promotion of independent living and community inclusion for PWMDs in their community. Further, Uganda's domestic legal framework is largely analogous with existing international and regional treaties and standards. The outstanding task is for government to implement the progressive laws and adopt programmatic measures that shift from the rhetoric to the tangible actualization of the legal guarantees.

Although the PWD Act, 2020 and MHA, 2019 are quite progressive, they have no explicit provision on the right to independent living and community inclusion as stipulated in Article 19 of UNCRPD and 14 of the ADP. This therefore calls for a purposive interpretation of the existing provisions of the various laws by legislators,

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[656] NUDIPU, 'Disability Demand', at 7; MDAC and MHU, 'They do not consider me a person', at 34-36.
[657] *Ibid*, at 7.
[658] UNCRPD Committee, General Comment No.6: para 70.
[659] Mpanga, 'PWDs in recruitment', at 74-76; NUDIPU, 'Disability Demands', at 14-15.

policy makers, and other government entities as they plan to mainstream services and programmes to meet government's aspirations of promoting disability inclusion in Uganda. In addition, judicial activism in breathing life into the progressive laws is paramount. Involving PWDs, irrespective of the nature of their disability in this discourse, is a critical step that must be adhered to. Without such activism and pragmatic interventions, the right to independent living and community inclusion will remain rhetoric in the ratified international and regional treaties, never to be realized in Uganda.

The next section explores the government programmatic initiatives in place to comply with the State obligations, as well as enable PWMDs improve their standard of living and be included in the community.

4.2 Examining the existing support programmes

The National Disability Policy (NDP), 2006 recognises several strategies towards implementing the policy and achieving community-based rehabilitation (CBR). These include: mobilising adequate resources; advocating for strengthening of positive cultural values that foster understanding, care and support for the protection of PWDs; strengthening and empowering PWDs and their caregivers; capacity building and enhancing social support so that PWDs participate in and contribute to socio-economic development; ensuring PWDs participation in planning, implementing, monitoring and evaluation of all initiatives; implementing interventions through communities, local authorities, Civil Society Organisations (CSOs), the private sector, the family and other actors so as to enhance capacity and increase the outreach.[660] In providing for care and support to PWDs, the National Development Plan (NDP) III emphasizes that care and support will include provision of basic physical and psychological needs to PWDs and their caregivers. It

[660] NDP, 'National Development Plan 111, 2020/21 – 2024/25': Clause 3.5, at 17.

also calls for the strengthening of capacities of families, communities and service providers to provide counselling and recreational facilities.[661]

In an effort to meet the aspirations of both laws and policies, the government has embarked on adopting initiatives that are indubitably fundamental in creating an environment that promotes independent living and community inclusion for PWDs.

4.2.1 Community Based Rehabilitation services (CBR)

Neither the UNCRPD nor the ADP define the terms rehabilitation, community-based rehabilitation services (CBRS) or community-based support services (CBSs). The National Disability-Inclusive Planning Guidelines define rehabilitation as a set of measures that assist individuals who experience, or are likely to experience, disability in achieving and maintaining optimal functioning in interaction with their environment.[662] This definition focuses on addressing the limitations caused by the individual impairment. The Ministry of Gender Labour and Social Development (MGLSD) defines CBR as a strategy for equalisation opportunities, poverty reduction, rehabilitation and social inclusion of PWDs in their communities.[663] Similarly, the WHO-CBR Guidelines note that CBR is a strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of PWDs.[664]

According to the WHO-CBR Guidelines, CBR is community action to ensure that persons with disabilities have the same rights and opportunities as all other community members. These include: equal access to health care, education, skills training, employment, family life, social mobility and political empowerment.[665] The WHO-CBR Guidelines further note that the key principles of CBR need to be poverty

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[661] *Ibid,* Clause 4.6(i), at 20.
[662] *Ibid*, 'Disability Inclusive Guidelines for Uganda'.
[663] Ministry of Gender Labour and Social Development, 'Social Development Sector Plan (SDSP) 2015/16-2019/20.'
[664] WHO, 'CBR Guidelines', at 2.
[665] *Ibid*, at 1.

alleviation, education, health and rehabilitation, and enabling people with disabilities to participate in a wide range of human activities.[666] The objective of CBR is to ensure inclusion of PWDs in the civil, social, political and economic structures of the community. This means PWDs playing a full part as citizens of their society with the same rights, entitlements and responsibilities as others, while contributing tangible benefits to the whole community.[667]

Originally, CBR largely focused on the medical needs of the person without addressing the socio-economic aspects.[668] However, reconceptualization of CBR has recognized the broader nature of needs of PWDs beyond health alone.[669]

CBR was first introduced in Uganda in 1991 by the Norwegian Association for the Disabled (NAD) in collaboration with the Ministries of Health, Education and Sports and the MGLSD.[670] The main objective of the programme at the time of initiation was to achieve full integration of *disabled persons* in the mainstreams of society by undertaking rehabilitation measures at community level that used and built on local resources available in the community.[671] The programme was also designed to ensure early identification, assessment and referral of all treatable disabilities for early management.[672]

Currently, the CBR programme to promote inclusion of PWDs is being implemented by the MGLSD.[673] The programme follows the WHO strategy in involving PWDs in the activities of their communities through equal access to community resources like education, health, rehabilitation and employment, and

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[666] *Ibid,* at 1.
[667] *Ibid*, at 2.
[668] Wickenden, Mulligan, Fefoame *et al*, 'CBR Guidelines and Ghana and Uganda', at 1.
[669] *Ibid*, at 1.
[670] Norwegian Association of the Disabled (NAD), 'CBR Programme in Uganda', at 6.
[671] *Ibid*, at 8.
[672] Ministry of Gender, Labour and Social Development, *Community Rehabilitation Programme for the Disabled,* http://www.mglsd.go.ug/programmes/community-rehabilitation-programme-for-the-disabled.html.
[673] The CBR programme was initiated in 1992 with the support from the Norwegian Association of the Disabled (NAD). The programme follows the WHO, 'CBR Guidelines'.

ensuring social inclusion.[674] The programme is being implemented in 25 districts across the country. These are: Kayunga, Mukono, Hoima, Nakasongola, Ntungamo, Mitooma, Kasese, Tororo, Kaliro, Kibuku, Arua, Kabale, Gulu, Kakumiro, Masaka, Buikwe, Wakiso, Bushenyi, Nshema, Rubirizi, Kyenjojo, Busia, Pallisa, Butaleja, Kibaale, Kanungu and Mbale.[675] The current CBR programme focuses on livelihood skills, education, health, social protection and empowerment.[676]

The MGLSD is supported by the District Rehabilitation Officers at the District level and the Community Development Officers and Community Volunteers at the community level in the implementation of the CBR Programme.[677] Kaggwa observed that:

> The programme has resulted into positive attitudes and acceptance of PWDs in the community, increased participation of PWDs in development activities, increased household income among PWDs, protection of the lives of PWDs to live a fulfilled life, ability of PWDs to demand and hold service providers accountable and reduction of poverty due to increase in income.[678]

However, an assessment of the programme revealed that it had not benefited persons with severe multiple disabilities, and those with psychosocial and intellectual disabilities.[679] The CBR Coordinator confirmed that due to stigma and negative stereotypes, PWMDs have not been reached by the programme.[680]

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[674]NAD, 'CBR Programme in Uganda', at 6; Abimanya and Mannan, 'Progress and Challenges', at 2.
[675] Presentation by CBR National Coordinator - MGLSD at a disability rights research seminar conducted on 22nd-June 2019, organised by the Disability Law and Rights Centre, School of Law, Makerere University.
[676] The MGLSD has developed the Draft Community-Based Rehabilitation Guidelines intended to operationalise the National Disability Policy. It is largely guided by the WHO, 'CBR Guidelines' which include components such as education, health, livelihood, social equity, social protection and empowerment.
[677] NAD,'CBR Programme in Uganda', at 9.
[678]Presentation by Ms. Beatrice Kaggya, Assistant Commissioner - Disability and Elderly, MGLSD.
[679] NAD, 'CBR Programme in Uganda', at 14.
[680]Presentation by the National CBR Coordinator, MGLSG, 22nd June 2019.

Furthermore, although this programme is applauded for extending some support to PWDs, it does not place emphasis on provision of CMHCS and has not benefitted PWMDs or their caregivers.[681] Besides the recent provisions in the MHA, 2019 (earlier discussed), Uganda has not yet developed a CMHCS policy or strategy to guide the provision of CMHCS and support services. Yet, CMHCS provides a more cost-effective and humane outcomes to PWMDs.[682] It can also pave the way for the realisation of the right to independent living and community inclusion of PWMDs in their communities.

4.2.2 Social support programme

To boost economic empowerment and mitigate high unemployment and poverty levels, government under the MGLSD provides some social assistance grants to vulnerable and disadvantaged groups. These include:

a) Special grant for PWDs

This grant was established in the Financial Year of 2009/2010, with the purpose of supporting income-generating activities of PWDs, providing employment, improving income status and enabling the PWDs to become partners in the development process of the country.[683] The government allocates three billion Uganda shillings (800 USD) annually to be shared by the different districts across the country. The funds are then allocated to the beneficiaries by the District Special Grants Committee, which targets vulnerable PWDs organized in groups.[684] According to NCD, a total of 800 registered PWD groups comprising 10-15 people per group were supported across the country between the period of 2015 to 2018.[685]

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[681] *Ibid*.
[682] Mansell, Beadle-Brown and Beecham *et al*, 'Deinstitutionalisation and community living – outcomes', at 11; MDAC and MHU, 'Psychiatric hospitals', at 44; WHO, 'Pyramid Framework', at 2; WHO, Guidance on Community mental health Services,' at 6.
[683] NCD, 'Performance of Special Grant for Persons with disabilities in improving their livelihoods in Uganda', at 9.
[684] *Ibid*, at 9.
[685]National Council For Disability (NCD), 'Disability Status Report', at 44-45.

Unfortunately, the report did not provide any statistics on the number of PWMDs who benefitted from the grant.

NCD also revealed that the grant initiative faced several challenges. These included: the increasing number of districts requesting grants, which reduced the level of funding available per district; mismanagement of the funds by group members; limited monitoring of the utilization of the funds by the groups; and lack of knowledge of the existence of the grant by some PWDs.[686] These obstacles undermined the realization of the purpose of the grant.[687]

b) The Youth Livelihood Programme (YLP)

This initiative is meant to enhance access to financial support for creation of jobs and business activities for the youth (persons between 18-35 years). In the Financial Year 2018/2019, the MGLSD supported a total of 6770 youth with disabilities.[688] In addition to the YLP, there is the vocational skills training offered by the government. A total of 600 youth with disabilities were provided with vocational skills training at the Vocational Rehabilitation Centre of Lweza, Ruti and Mpumudde.[689] However, it is not clear how many of the beneficiaries were youth with mental disabilities.

c) The Uganda Women Entrepreneurship Programme

Under this initiative, every women's group accessing the funds must include a woman with a disability. Since 2016, 50 billion Uganda Shillings (13,800 USD) has been rolled out for this initiative, and this is set to continue for another five years.[690] The groups comprise 10-15 women, and largely target unemployed women and vulnerable groups such as single young mothers, widows, women with disabilities, women living with HIV/ AIDS, and slum dwellers. By October 2018, a total of 85,336 targeted beneficiaries of which 7.5% were women with disabilities benefitted from

[686] *Ibid,* at 22-24.
[687] *Ibid*, at 22-24.
[688] *Ibid*, at 45.
[689] *Ibid,* at 45.
[690] *Ibid*, at 45.

this empowerment scheme.[691] However, there is no available data on the number of women with mental disabilities who have accessed the grant.

d) The Parish Development Model

The Parish Development Model (PDM) is the most recent economic empowerment initiative by the government. The PDM has seven Pillars. These are: (a) Production, Storage, Processing and Marketing; (b) Infrastructure and Economic Services; (c) Financial Inclusion; (d) Social Services; (e) Mindset change; (f) Parish Based Management Information System (g) Governance and Administration.[692] In this programme, seventeen million Uganda shillings (17,000,0000), which is approximately USD 4600, will be given to each Parish in this first financial year, and then subsequently one hundred million (100,000,000/=), which is approximately USD 28,000, in the next financial year to support development activities geared towards eradicating poverty from the Parish level.[693] There about 10,594 Parishes in the country. It is hoped that with the PDM trickling down to the lowest level, it will foster economic development from the grassroots.[694] Commendably, the government has been keen in ensuring that the PDM is allocated equitably among the various vulnerable groups. That is, 10% for PWDs, 30% for women, 30% for youth, 10% elderly persons and then 20% for men groups. However, individuals can still access the funds from the different categories and other economic initiatives.[695]

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[691] *Ibid*, at 44-45.
[692] MGLSD, 'Implementing Guidelines for the Parish Development Model' (June 2021), Available at https://www.masindi.go.ug/sites/default/files/Implementation_Guidelines_for_FOR__PARISH_MODEL_OPERATION%5B1%5D.pdf. (Accessed on 26th November 2022).
[693] MGLSD, 'Implementing Guidelines for the Parish Development Model' (June 2021), Business Focus, 'President Launches the Parish Development Model (PDM)' published on 22nd February, 2022. Available at https://businessfocus.co.ug/president-museveni-launches-parish-development-model/.(Accessed on 26th November 2022)
[694] Ibid.
[695] The Nile Post, Government assures PWDs special status in the Parish Development Model Programme', by Keneth Kazibwe. 18th May 2022. Available at https://nilepost.co.ug/2022/05/18/govt-assures-pwds-of-special-status-in-parish-development-model-program/ (Accessed on 2nd December 2022).

Unfortunately, although these empowerment programmes are largely meant to support vulnerable groups, including PWMDs, none is specific to the unique needs of this category or their caregivers. Except for the newly launched PDM, there is also no data to confirm access of these grants by PWMDs or their care givers. It is hoped that government's renewed commitment to ensure economic empowerment for all PWDs will identify and cure this lacuna.[696]

4.3 Conclusion

Clearly, Uganda can boast of a progressive legal framework and political commitment towards the protection of the rights of all PWDs. The government programmes to support CBR, and economic empowerment initiatives among vulnerable groups are very laudable. However, provision of CMHCS, coupled with accessible environment and social amenities, in addition to CBS, are critical enablers for the realization of the right to independent living and community inclusion for PWMDs. What is concerning is that Uganda has neither developed a CMHCS policy or strategy, nor expressly provided for the right to independent living and community inclusion in its domestic legislations. It is contended that this lacuna is a major inhibitor to the provision of CMHCS and promotion of disability inclusion in the country. Hence, the laudable provisions in the MHA, 2019 on provision of CMHCS may not yield much transformation without the political will to adequately invest in the mental health care sector. Consequently, there is need to evaluate and monitor the impact of these laws, policies and programmes in transforming the lives of PWMDs and promoting their independent living and community inclusion in Uganda. In so doing, best practices can be drawn from other jurisdictions to improve Uganda's efforts.

South Africa and Kenya have made some significant strides in protecting the rights of PWMDs, provision of CMHCS and promotion of the right to independent living and community inclusion. The following chapter examines the legislative and programmatic

[696] MGLSD, 'Renewed Government Commitment', at 16.

measures adopted by the two countries to promote the realisation of the right to independent living and community inclusion for its PWMDs.

CHAPTER FIVE

COMPARATIVE ANALYSIS: LESSONS FROM SOUTH AFRICA AND KENYA

> *The global burden of disease attributable to mental disorder has risen in all countries in the context of major demographic, environmental, and social-political transition. Human rights violations and abuses persist in many countries, with large number of people locked away in mental institutions or prisons, or living on the streets, often without legal protection…Collective failure to respond to this global health crisis results in monumental loss of human capabilities and avoidable suffering. (per Lancet Commission Report on Mental Health and Sustainable Development, Patel et al, (2018): 1553)*[697]

5.0 INTRODUCTION

This chapter undertakes a comparative analysis of best practices adopted by South Africa and Kenya in providing CMHCS and protecting the right to independent living and community inclusion for PWMDs. These jurisdictions are chosen because of their political, economic, legal and social similarity with Uganda. Kenya neighbours Uganda to the East, and both are Member States of the East African Community (EAC). South Africa, on the other hand, belongs to the Southern African Development Community (SADC). All the three States were British colonies and inherited many of their laws and policies from their former colonial master.[698] They are all categorised as developing countries,[699] and are party to the same international and regional human rights instruments, including the UNCRPD.[700] South Africa has signed the ADP, but is yet to ratify the instrument.[701] Kenya and Uganda have neither signed nor ratified the ADP.[702]

The comparative analysis of the selected countries addresses four thematic areas: (a) the state of mental health and institutionalisation of PWMDs; (b) the extent

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[697] Pillay, 'Mental health in South Africa', at 464.
[698] South Africa, Uganda and Kenya attained independence from the British colonial masters in 1961, 1962 and 1963 respectively.
[699] United Nations, 'Country Classifications (2014).'
[700] South Africa ratified the UNCRPD on 30th November 2007 and Kenya ratified the same instrument on 19th May 2008.
[701] See AU status List of countries that have signed, ratified or acceded to the Protocol: South Africa signed on 29th April 2019.
[702] *Ibid.*

to which the existing legal and policy framework guarantees the right to independent living and community inclusion of PWMDs; (c) the state of community mental health care and support services; and (d) an examination of the available programmatic measures to promote independent living and community inclusion of PWMDs in society.

5.1 SOUTH AFRICA

5.1.1 The State of Mental health and the Institutionalisation of PWMDs in South Africa

South Africa, like Uganda, continues to grapple with the prevailing state of marginalisation, discrimination and poverty faced by PWDs in society.[703] According to the country's 2011 census, PWDs comprised about 7.5% of the national population of 51,800,00 million people.[704] Like is the case in Uganda, the South African census report did not indicate specifically the composition of PWMDs.[705] However, the South African Human Rights Commission (SAHRC) reports that 17 million people in the country are dealing with a form of mental illness, including depression, substance abuse, anxiety, bipolar disorder and schizophrenia illness.[706]

Similar to Uganda, there is limited access to mental health care services in South Africa as the sector is inadequately resourced.[707] Fifteen percent of PWMDs have been institutionalised in mental facilities or special residential homes.[708]

According to the WHO, there are 9.3 mental health workers per 100,000 population. This comprises of the following: 0.28 psychiatrists, 0.45 other medical

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[703] Swanepoel, 'Mentally ill Patients in South African', at 2; Ministry of Social Development, *White Paper on the Rights of PWDs (MOSD: WPRPWDs)* approved by Cabinet in 2015. It replaced the White Paper on an Integrated National Disability Strategy (INDS) which was released on 3rd December 1997 and it was to be implemented by the Office on the Status of disabled Persons (OSDP) in the presidency, at 20-24; Burns, 'Mental health gaps in South Africa', at 99.

[704] South Africa (SA) Census report 2011,'at 14 note that the national census is conducted every 10 years.

[705] SAHRC Report, 'Investigating Mental Health in South Africa', at 27.

[706] *Ibid*, at 27.

[707] South African College of Applied Psychology, 'The Shocking State'.

[708] United Nations Department of Economic and Social Affairs Report, 'Disability and Development Report: Realising Sustainable Development Goals by, for and with PWDs', at 208.

doctors (not specialised in psychiatry), 7.45 nurses, 0.32 psychologists, 0.4 social workers, 0.13 occupational therapists, 0.28 other health and mental health workers and with specialised mental health care training.[709] The mental health care workers are primarily concentrated in urban areas.[710] The statistics clearly show that there is a small pool of suitable health professionals to deal with the many demands for mental health care, treatment and rehabilitation in the country. The report further reveals that there is inadequate funding to the health sector.[711] It is thus unsurprising that the SAHRC noted that only 25% of the mentally ill receive treatment.[712] The Commission identified a mental health treatment gap, which it attributed to factors such as: insufficient budget allocation to the sector; poor mental health literacy and lack of information; stigma and discrimination; limited human resources; and insufficient facilities providing mental health services.[713] Decrying the state of mental health care in South Africa, Burns observed that:

> The gaps in the mental health sector have resulted into psychiatric hospital remaining outdated, falling into disrepair and often unfit for human use; there is serious shortages of mental health professionals; an inability to develop vitally important tertiary level psychiatric services; and community mental health and psychosocial rehabilitation services remaining underdeveloped, so that patients end up institutionalised, without hope of rehabilitation back into their communities.[714]

Like is the case in Uganda, institutionalisation in mental health facilities remains the primary mode of management of PWMDs in South Africa. The WHO-AMIS report revealed that there are 23 mental hospitals in South Africa, with 56% of the mental health beds located within these facilities; 13% in other residential facilities; 11% in community residential facilities; 11% in forensic units, and 9% in

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[709] WHO, AMIS, 'Mental Health systems in South Africa', at 17; SAHRC Report: Investigating Mental Health in South Africa,' at 30.
[710] *Ibid*, at 17; SAHRC Report, 'Investigating Mental Health in South Africa', at 30.
[711] *Ibid*, at 9; SAHRC Report, 'Investigating Mental health in South Africa' at 32.
[712]SAHRC Report, 'Investigating Mental health in South Africa', at 27.
[713] *Ibid,* at 27.
[714] Burns, 'Mental health gaps in South Africa', at 104, 106; Docrat, Besada, Cleary *et al*, 'Cost, Resources and Constraints in South Africa', at 708.

community based psychiatric in-patient units.[715] The shortcomings in the South African mental health sector hinders efforts towards an effective deinstitutionalisation process and curbing the 'revolving door' phenomenon, [716] provision of CMHCS and support services, and promoting the right to independent living and community inclusion.[717]

This dilemma manifested in the Life Esidimeni tragedy, in which, under the Gauteng Mental Health Management Project, an estimated 1371 PWMDs were rapidly transferred from the Life Esidimeni facility to NGOs, some of which were unlicensed or unfit to provide community mental health care services. Following reports of neglect, abuse, under-capacitation and under-resourcing, 143 PWMDs died in the process and another 49 remain unaccounted for to-date.[718] This incident also confirmed that the community-based residential or 'step-down' facilities are significantly under-resourced and poorly regulated.[719] Indeed, Ferlito rightly observed that the Life Esidimeni incident confirmed that Gauteng Department of Health (GDOH) fell short of their legal and moral obligations by negligently placing the care of their patients in the hands of incompetent people and/or facilities that lacked the necessary capacity.[720] Decrying the conditions of institutionalisation in South Africa, the UNCRPD Committee in their Concluding Observations urged the country to[721],

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[715] WHO, AMIS Report, 'Mental health Systems in South Africa', at 14; Burns, 'The Mental Health Gap in South Africa', at 103-104; The Mental Health and Poverty Project (MHaPP), 'Promoting community-based services in South Africa', at 2.
[716] Lund, Kleintjes, Cooper *et al*, 'Challenges facing South African's mental health care systems', at 31-33.
[717] MHaPP, 'Promoting community-based services in South Africa', at 3.
[718]Ferlito and Dhai, 'Esidimeni: Human rights perspective', at 54; Duroyaye and Kabagambe, 'Contributions of Health Ombuds', at 161-168. Ferlito and Dhai, 'Some ethical transgressions', at 157.
[719] SAHRC report, 'Investigating Mental Health in South Africa', at 27.
[720] Ferlito and Dhai, 'Esidimeni: Human Rights Perspective', at 52-54; Durojaye and Kabagambe, 'Contribution of the Health Ombud', at 161-168; Ferlito and Dhai, 'Some ethical transgressions', at 157.
[721] UNCRPD Country Specific Concluding Observations. Available at https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5.

a. Develop and adopt a national strategic and legislative framework on deinstitutionalization of persons with disabilities, including all the necessary independent living community support services.
b. -Ensure that persons with disabilities are effectively included, through their representative organizations, at all stages of the deinstitutionalization process;
c. - Adopt an action plan at the national, regional and local levels to develop community support services in urban and rural areas, including providing personal assistance, grants and support to families of children with disabilities and parents with disabilities, covering support for assistive devices, guides and sign language.

In view of the shortcomings arising from this incident, commentators have suggested several strategies to address the challenges in the South African mental health sector. They have stressed the importance of high-level political endorsement of a comprehensive national mental health policy; the need for identifying the social determinants of mental illness; public education and awareness raising strategies to combat stigma; the integration of mental health into primary health care; and the development of well-resourced community-based care with the support of NGOs.[722] Commentators have also stressed the need to have adequate and correct data and information about the health expenditure and coverage for better forward-planning.[723]

Evidently, the shortcomings in the South African mental health sector include: discrimination and marginalisation of PWMDs; inaccuracy of data specific to PWMDs; inadequate funding of the mental health sector; over- institutionalisation under the medical model of disability; a need for comprehensive community-based mental health care and support services for PWMDs; and a lack of a clear deinstitutionalisation strategy to promote independent living and community inclusion of PWMDs. These shortcomings are similar to those experienced in Uganda. It thus appears that both Uganda and South Africa need to adopt robust

[722] Lund, Kleintjes, Cooper *et al*, 'Challenges facing South African mental health Systems', at 36; Pillay, 'State of Mental health and illness in South Africa', at 466.
[723] Docrat, Besada, Cleary *et al*, 'Mental health Systems: Cost, Resources and Constraints in South Africa', at 718.

measures to address the gaps in the sector to enhance access to mental health care, as well as protect the dignity and rights of PWMDs.

Commendably, however, like Uganda, South Africa can take pride in its adoption of progressive legal and policy frameworks that would be able to promote and protect the rights of PWMDs. This is discussed in the next section.

5.1.2 Legal and Policy Frameworks on Mental Health in South Africa

South Africa, like Uganda, is party to various international and regional human rights treaties and conventions,[724] which enjoins her to recognise human diversity and protect the rights of all PWMDs.[725] It has also passed several progressive domestic laws that guarantee the rights of PWDs generally and PWMDs in particular. This section examines the extent to which the laws protect the rights of PWMDs, guarantee the provision of CMHCS, and protect the right to independent living and community inclusion for PWMDs in South Africa.

I. The Constitution

Adopted in 1996 after the apartheid era, the South African Constitution[726] premises its values on human dignity and the achievement of equality, the advancement of human rights and freedoms for all while recognising the diversity in the society.[727] This is critical, since PWMDs form part of the human diverse race and must be treated with dignity too. The Constitution contains a Bill of Rights which sets out the rights and fundamental freedoms accorded to all persons, and the

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[724]The 1945 UN Charter; the UDHR; UNCRPD ratified on the 30th November 2007; Optional Protocol to the UNCRPD accepted on 30th November 2007; ICESCR signed on 3rd October 1994 and ratified on 12th December 2015; ICCPR signed on 3rd October 1994 and ratified on 10th December 1998; UNCRC signed 29th January 1993 and ratified on 16th June 1995; UNCAT signed on 29th January 1993 and ratified on 10th December 1998; CEDAW signed 29th January 1993 and ratified on 15th December 1995. At the regional level are the ACHPR ratified on July 09, 1996; the Maputo Protocol ratified on 17 December 2004; the ACRWC ratified on 7th January 2000, among others.

[725] Burns, 'The Mental Health Gap in South Africa', at 99, 106. It is worth noting that under Sections 231(2) and (4) of the South African Constitution, international agreements are binding subject to approval by the National Assembly and National Council of Provinces and adoption into law.

[726] The Constitution of the Republic of South Africa, 1996.

[727] Section 1(a).

corresponding duty on the State to respect, protect, promote and fulfil the rights.[728] The thesis focuses on the rights that have a bearing on the realisation of the rights to independent living and community inclusion for PWMDs such as: the right to equality of all persons before the law,[729] prohibition from any form of unfair discrimination of any persons on any ground including disability,[730]the right to inherent human dignity,[731]the right to life,[732]freedom from arbitrary detention, and any form of violence by private or public actors, freedom from torture, inhuman and degrading treatment;[733]the right to access adequate housing,[734] the right to access health care,[735] right to education,[736] and the right to seek redress before any court of competent jurisdiction.[737] Commendably, the Constitution explicitly prohibits discrimination on grounds of disability. Section 9(3) states that,

> The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including …disability….

Laudably, this constitutional safeguard is buttressed by the stipulations in the Promotion of Equality and Prevention of Unfair Discrimination (PEPUDA/the Equality Act)[738] which sets out to combat all forms of inequality and unfair discrimination in order to achieve a democratic society.[739] The PEPUDA defines discrimination to mean,

> Any act or omission, including a policy, law, rule, practice, condition or situation which directly or indirectly,
>
> a. Imposes burdens, obligations or disadvantage on; or
> b. Withholds benefits, opportunities or advantages from

[728] Chapter 2, Sections 7 (1 and 2) and 8.
[729] Section 9(1).
[730] Sections 9(3) which provides that, 'the State may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including disability among others.'
[731]Section 10.
[732] Section 11.
[733] Section 12 (1 a, c, d and e).
[734] Section 26.
[735] Section 27.
[736] Section 29.
[737] Section 38.
[738] Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000.
[739] Kok, 'The Promotion of PEPUDA', at 451.

any person on one or more of the prohibited grounds

It broadly defines equality to mean the full and equal enjoyment of rights and freedoms as contemplated in the Constitution and includes *de jure* and *de facto* equality and also equality in terms of outcomes,[740] hence ensuring substantive and not formal equality alone.[741] Like the Constitution, the PEPUDA prohibits discrimination on various grounds, including disability. Section 9 stipulates that:

> Subject to section 6[742], no person may unfairly discriminate against any person on the grounds of disability, including
>
> a. Denying or removing from any person who has a disability, any support or enabling facility necessary for their functioning in society
>
> b. …
>
> c. Failing to eliminate obstacles that unfairly limit and restrict persons with disabilities from enjoying equal opportunities or failing to make steps to reasonably accommodate the needs of such person.

The South African law enjoins both the State and non-State actors to ensure that non-discrimination and substantive equality are enjoyed by even PWMDs in the country. This suggests an obligation to adopt measures that promote CMHCS and deinstitutionalisation, as well as to create a favourable environment for the enjoyment of the right to independent living and community inclusion for PWMDs.

II. The Mental Health Care Act, 2002

Following numerous inspections, consultations and recommendations of the Van Wyk Commission,[743] as well as the 1997 White Paper of the Health Department that called for development of comprehensive community-based mental health services

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[740] Section 1.

[741] As stated in the Preamble, the Act endeavours to facilitate the transition to a democratic society, united in its diversity, marked by human relationships that are caring and compassionate, and guided by the principles of, fairness, equality, social progress, justice, human dignity and freedom.

[742] Section 6 provides general provision on unfair discrimination of any person by either the State or non-State actor.

[743]Haysom, Strous and Vogelman, 'The Mad Mrs. Rochester Revisited', at 343; Schedule to the MHCA listing the laws repealed by the Act to include: The Mental Health Act , No.18 of 1973 (Except for Chapter 8), The Mental Health Act N0.19 of 1981 (Truskie), The Mental Health Act N0.26 of 1985 (Bophuthatswana), Mental Health Act No.23 of 1986 (Ciskei).

and integrated with other health services,[744] the Mental Health Act, 1973 was repealed and replaced by the current Mental Health Care Act (MHCA) of 2002[745] (as amended by the Mental Health Care Amendment Act of 2014).[746] Worth noting is that the MHCA, 2002 was adopted prior to South Africa's ratification of the UNCRPD.[747] However, several authors commended the passing of the MHCA, 2002, contending inter alia that it addresses the racial segregation in the provision of treatment to PWMDs;[748]provides a human rights approach to care and accountability in line with the 1996 Constitution;[749] and a patient-centred approach to psychiatric care.[750] It is imperative therefore, to appreciate the extent to which the Act conforms to the aspirations of UNCRPD and the ADP, particularly in promoting the right to independent living and community inclusion of PWMDs.

In its long title, the MHCA, 2002 sets out to provide for the care, treatment and rehabilitation of persons who are mentally ill; to set out different procedures to be followed in the admission of such persons; to establish a Review Board with respect to every health establishment; to provide for the administration of the property of the mentally ill among others.[751]

In line with the WHO definition of 'health', the Act broadly recognises that health includes a state of physical, mental and social well-being and that mental health services should be provided as part of the primary, secondary and tertiary services.[752] This is pertinent to enable easier access and availability of mental health services at all levels in the community.

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[744] Simpson and Chipps, 'Mental Health Legislation in South Africa', at 49.
[745] Act 17 of 2002.
[746] Act 12 of 2014, assented to on 28th October 2002 and commenced on 15th December 2004. It is operationalised by General Regulations passed in 2004.
[747] Ratification date is 30th November 2007.
[748] Ramlall, 'Trials and Triumphs', at 407-410.
[749] Szabo and Kaliski, 'Mental Health and the Law: A South African Perspective', at 71; Ramlall, 'Trials and Triumphs', at 408.
[750] Simpson and Chipps, 'Mental Health Legislation in South Africa', at 47.
[751] Long title to the MHCA and Section 3 on Objectives of the Act.
[752] Preamble to the MHCA.

The MHCA also has a number of provisions that create room for the provision of CMHCS and the realisation of the right to independent living and community inclusion as discussed below:

a) Providing for integrated and community-based mental health care

To fight stigma and promote comprehensive integration of mental health care in the community, the MHCA emphasizes the need to provide care, treatment and rehabilitation services in a manner that facilitates community care of mental health care users.[753] Section 3 spells out the objectives of the MHCA, which include inter alia:

a. To regulate the mental health care in a manner that,

    i. makes the best possible mental health care, treatment and rehabilitation services available to the population equitably, efficiently and in the best interest of the mental health care user within the limits of the available resources
    ii. co-ordinates access to mental health care, treatment and rehabilitation services to various categories of mental health care users; and
    iii. integrate the provision of mental health care services into the general health service environment

b. regulate access to and provide mental health care, treatment and rehabilitation services to: voluntary, assisted, involuntary mental health care users; State patients and mentally ill prisoners

In addition, section 4 of the Act places a duty on all State organs in the provision of health services to determine and coordinate the implementation of its policies and measures in a manner that among others:

a. Ensure the promotion of mental health care, treatment and rehabilitation at primary, secondary and tertiary levels and health establishments;
b. Promote provision of community-based care, treatment and rehabilitation services
c. Promote the rights and interests of mental health care users and promote; and
d. Improve the mental health status of the population.

[753] Section 6(8) and Regulation 5 of the MHCR Regulations.

To facilitate availability and accessibility of CMHCS, both State and non-State actors are encouraged to run community programmes that may include: medical care, residential community accommodation, day-care centres, counselling, support and therapeutic groups, psychotherapy, vocational rehabilitation programmes, psychosocial rehabilitation programmes and other services which would assist recovery of a person to optimal functioning in the community.[754] Notably, the Act seeks to ensure that care, treatment and rehabilitation of PWMDs is accessed by all without discrimination and in accordance with the Constitution. Ramlall applauds the Act for recognising the need for comprehensive community-based mental health care, integration of mental health services in general health care to enhance accessibility and fight stigmatisation.[755] It is also contended that the integration of mental health care in general health services and provision of comprehensive CMHCS in the least restrictive environment can reduce the stigma associated with mental health problems, is cost-effective compared to institutionalisation, and improves recovery and dignity of the PWMDs.[756] Indubitably, a strong system of CMHCS, coupled with primary health care services, is vital to support de-institutionalisation and the integration of PWMDs into the primary health care system and community inclusion.[757] However, deinstitutionalisation, if not matched with the relevant and adequate resources to support CMHCS and support for PWMDs, may lead to human rights violation.[758] Furthermore, the absence of a CMHCS in reality also burdens service provision within the facility-based health centres, putting additional pressure on the already stretched primary health services

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[754] Regulation 5(2) and (3).
[755] Ramlall, 'Trials and Triumphs', at 408. Section 6(8) also enjoins persons providing care, treatment and rehabilitation services to provide such services in a manner that facilitates community care of MHCUs.
[756] Simpson and Chipps, 'Mental Health Legislation in South Africa', at 51.
[757] *Ibid*, at 53.
[758]UNCRPD Committee, General Comment No. 5: para 33; Ferlito and Dhai, 'The Courts are also to blame', at 155-156; Lund, 'A hidden Human Rights Crisis', at 403-405.

and hospital beds, and may result in a 'revolving door' pattern, with adverse consequences for provision of quality care.[759]

Unfortunately, despite the elaborate provision for CMHCS, there is still a huge gap in reality.[760] Lund and Flisher assert that CMHCS in South Africa is generally under-resourced and inequitably distributed and the focus remains on institutional settings in urban areas.[761] Hence, there remains a need for the redirection of current mental health resources in South Africa from hospitals to the provision of CMHCS and support services.[762]

These shortcomings in the provision of CMHCS is similar to those in Uganda. Although provision of CMHCS is stipulated in Uganda's MHA 2019,[763] this is yet to be effected.[764] Hence, the need for both States to embark on robust measures to promote CMHCS for PWMDs.

b) Use of less derogatory terms

As noted earlier, derogative terminologies used against PWMDs perpetuates disempowerment, dehumanisation, exclusion and marginalisation.[765] To uphold the human dignity, non-discrimination and combat stigmatisation against PWMDs, the South African MHCA uses progressive and less derogatory terminologies. Firstly, the MHCA, 2002 provides a comprehensive understanding of mental health to mean:

> the level of mental well-being of an individual as affected by physical, social and psychological factors and which may result in psychiatric diagnosis.[766]

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[759] MHaPP, 'Promoting community-based services for mental health in South Africa', at 3.
[760] Lund and Flisher, 'A Model for CMHCS in South Africa', at 1041.
[761] *Ibid*, at 1041.
[762] Lund and Flisher, 'Norms of mental health', at 591.
[763] Section 3(f), 4 and 20 of MHA 2019.
[764] Twinomugisha, 'Health and Human Rights Critique', at 14-15; Ojok, 'Mapping and Assessment', at 27-28.
[765] Naggita, 'The Solution is the Problem', at 77.
[766] Section 1(xx).

Mental illness, on the other hand, is defined as a positive diagnosis of mental health related illness in terms of accepted diagnostic criteria made by a mental health care practitioner authorised to make such diagnosis.[767] Further, it adopts the term mental health care users (MHCUs) to mean,[768]

> A person receiving care, treatment and rehabilitation services or using health services at a health establishment aimed at enhancing the mental health status of the user, state patient and mentally ill prisoner and where the person concerned is below 18 years or is incapable of taking decisions, and in certain circumstances may include:
>
> i. The prospective user
> ii. The person's next of kin
> iii. A person authorised by any other law or court order to act on behalf of someone
> iv. An administrator appointed in terms of this Act; and
> v. An executor of that deceased person's estate and "user" has a corresponding meaning

Laudably, the definition encompasses both the individual with mental illness and other persons who may be acting on the individual's behalf. The inclusion of support persons as MHCUs curtails stigma and also enhances access to services to meet the objectives of the Act. The use of a broad and non-derogatory terminology is applauded by various authors for enabling the transition from labels that perpetuate social stigmatisation and reducing access to mental health services. For instance, the Act uses the term 'mental health care user' instead of 'patient'. Szabo and Kaliski explain that although the word 'user' has somewhat negative connotations, in an attempt to seemingly be more egalitarian in the approach to care, it was clearly felt that the word 'patient' conferred a status not befitting an individual seeking and requiring care.[769] Similarly, Simpson and Chipps noted that,

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[767] Section 1(xxi). Under Section 1, a 'mental health care practitioner' means a psychiatrist or registered medical practitioner or a nurse, occupational therapist, psychologist or social worker who has been trained to provide prescribed mental health care, treatment and rehabilitation. A 'mental health care provider', on the other hand, means a person providing mental health care services to MHCUs and includes mental health care practitioners.
[768] Section 1(xix).
[769] Szabo and Kaliski, 'A South African Perspective', at 1.

> The new terminology in the MHCA referring to mentally ill patients as 'mental health care users'…while some might say is purely semantics, it was an attempt to move away from the hurtful labels that set apart people with mental health problems.[770]

Consequently, this approach upholds human dignity and empowerment of PWMDs, which is pertinent to their ability to live independently and be included in the community on an equal basis with others. It also enhances access to mental health care services.[771]

c) Protecting the rights of PWMDs

Influenced by the human rights discourse of the time, the MHCA commendably devotes a complete section on the rights and duties of MHCUs, as well as the need to observe their best interests.[772] It guarantees various rights such as: respect for human dignity and privacy, and provision of the least intrusive care, treatment and rehabilitation services that facilitates integration into community life;[773] the right to consent to health care, treatment and rehabilitation services unless where the MHCU is unable to consent and any delay may result in death or irreversible harm to the MHCU inflicting serious harm on himself or herself or others, or causing serious damage to or loss of property belonging to him, her or others;[774] protection from unfair discrimination due to mental health status and the right to receive health care, treatment and rehabilitation which is equivalent to those applicable to other health care users;[775]and freedom from exploitation and abuse, degrading treatment and

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[770] Simpson and Chipps, 'Mental Health Legislation in South Africa', at 50.
[771] *Ibid*, at 50.
[772] Chapter 3, Section 7.
[773] Section 8.
[774] Section 9(1). *See*, Section 9(2) which provides that where care, treatment or rehabilitation is provided without the MHCUs consent, an application must be made with twenty-four hours by the health provider to the Review Board for its decision.
[775] Section 10.

forced labour.[776] It further permits any person who witnesses such form of abuse of a MHCU to report the matter in accordance with the law.[777]

This is similar to the human rights guarantees in Uganda's MHA, 2019. However, the rights spelt out in South Africa's MHCA, 2002 are not exhaustive and must be read together with those set out in the Constitution, the PEPUDA and other relevant laws.[778]

To further enhance protection for PWMDs, the MHCA, 2002 provides for the establishment of a Review Board with a mandate to, among others: monitor the operations of the health service providers; consider appeals against the decisions of the head of health establishments; make decisions with regard to assisted or voluntary mental health care, review treatment and rehabilitation services; consider reviews and make decisions on assisted or involuntary MHCUs among others.[779]

The review and appeal process set out in the Act gives service users a right to representation and a right to appeal against the decision made by a medical practitioner concerning their care.[780] The quasi-judicial mandate of the review board is applauded as a mechanism to ensure that the rights of mental health users are protected, and actions are taken in their best interest.[781] Szabo and Kaliski observe that, despite the administrative burden in managing the process of assisted and involuntary care, the review board provides an oversight role of ensuring that the rights of users are respected and the Act is implemented appropriately.[782]

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[776] Section 11(1).
[777] Section 11(2).
[778] Section 7(2).
[779] Section 19.
[780] Jack-Ide, Uys and Middleton, 'A Comparative Study of Mental Health', at 50-57.
[781] Simpson and Chipps, 'Mental Health Legislation in South Africa', at 51; Spamer, 'A Critical Analysis', at 273; Ramlall, Chipps and Mars, 'Impact of South African Mental Health Care Act', at 667-70.
[782] Szabo and Kaliski, 'A South African Perspective', at 71; Also see sections 25-29, 35 on the process of voluntary, assisted and involuntary admissions and care.

However, the limited funding to the review board constraints the effective execution of its mandate as observed by SAHRC:

> The celebrated enactment of the MHCA falls short of realising the guarantees therein. For instance, the review board though applauded as a potentially useful mechanism for seeking recourse, these bodies have been shown to be dysfunctional in numerous instances, because of the unavailability of board members due to poor resource to facilitate their work.[783]

In Uganda's case, the Mental Health Advisory Board, which has a mandate similar to the South African Review Board, is still a mere 'paper tiger'. Although it is provided for under section 5 of the MHA, 2019 with a broad administrative and quasi-judicial mandate as spelt out in section 9, it still remains on paper. The membership of the board is yet to be constituted. It is acknowledged the MHA, 2019 is new, and its implementation was interrupted by the outbreak of Covid-19 which saw all the national attention and focus shifting to containing the virus. However, in light of the increasing demand for mental health care and vehement call for improvement in the sector, it is hoped that the establishment of the Board will indeed be actualised soonest, with adequate funding to enable it execute its mandate and enhance the protection of the rights of PWMDs.

[783] SAHRC Report, 'Investigating mental health care South Africa', at 20.

d) Recognising the role of the family and other care givers

In most African countries, the family bears the burden of caring for their member with disability, including the mentally ill.[784] Hence, the critical role played by the family as primary caregivers in ensuring access to mental health care and support services by MHCUs, adherence to medication, supporting deinstitutionalisation and community-based care and enabling independent living and community inclusion for PWMDs cannot be disregarded. Commendably, the South African MHCA 2002, just like the Ugandan MHA 2019, provides for the role of the family or caregivers at admission of MHCUs; submitting an application for admission and consent to treatment; applying for discharge of MHCUs and even lodging complaints on behalf of an aggrieved MHCU before any court or the Review Board.[785]

Unfortunately, there is no stipulation in the MHCA 2002 that imposes an obligation on the State to provide support to families or caregivers of PWMDs in order to lessen the burden of care. However, the UNCRPD Committee has emphasized that the State obligation to fulfil includes the empowerment of family members to support the family member with disabilities to realise their right to independent living and being included in the community.[786] Furthermore, the lack of CMHCS increases the burden of care on the family and has a negative impact on the user's wellbeing.[787] Also, caregiving may result in the inability of the caregiver to engage in gainful employment, or societal stigma that result from caring for a PWMDs in the home or within the community.[788] It is important therefore, that the family receive adequate financial as well as psychosocial support from the State in order to cope with the economic and social burdens of caring for a relative with a disability. Commendably, South Africa boosts of the disability grant, child

[784] Alem, 'Community-based vs Hospital-based mental health care', at 99.
[785] Sections 27, 29, 33 and 35.
[786] UNCRPD, General Comment No. 5: paras 55 and 68.
[787] MHaPP, 'Promoting community-based services for mental health in South Africa', at 3.
[788] Kock, 'De-institutionalisation of People with mental illness', at 74; Inclusion International, 'Global report on Article 19', 25-27.

dependency grant, child support grants provided for under the Social Assistance Act,[789] but their adequacy is discussed in detail later.

Uganda, unlike South Africa, has no disability grant or strategy to facilitate provision of support to families providing care to PWDs generally and specifically PWMDs. Hence, the need to adopt relevant measures.

5.1.3 The National Mental Health Policy Framework and Strategic Plan 2013- 2020

Strong mental health activism for better management of mental health in South Africa led to the adoption of the National Mental Health Policy Framework and Strategic Plan 2013-2020 (NMHPFSP).[790] The Vision of the policy is:

> To improve mental health for all South Africans by 2020 through employing various interventions that promote the rights, care, treatment and rehabilitation of PWMDs in South African in partnership with various stakeholders including the mental health user and provider and communities.

It lays out a number of objectives including: to scale up funding for decentralised integrated primary health care services, which include community based care;[791] primary health clinic care, and district hospital level care; to increase public awareness regarding mental health and reduce stigma and discrimination associated with mental illness; to promote mental health through collaboration between departments of health and other sectors; to empower local communities, especially mental health service users, to participate in promoting mental wellbeing and recovery within their communities; to promote and protect the human rights of people living with mental illness; to adopt a multisectoral approach to tackling the vicious cycle of poverty and mental illness; to establish a monitoring and evaluation

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[789] Act 13 of 2014.

[790] Stein, 'A New Mental Health Policy', at 115-116; WHO, AMIS 'Report on Mental Health in South Africa' at 25; Lund, Kleintjes, Cooper *et al* , 'Challenges Facing the South African Mental Health Systems'; Burn, 'The Mental Health Gap in South Africa-A Human Rights Issue'.

[791] The Policy defines community-based care as care that is provided outside institutional or hospital settings, and as near as possible to the place where people live, work and study.

system for mental health care; and to ensure that the planning and provision is mental health care is evidence based.[792] Laudably, the objectives of the Policy, like the MHCA 2002, place emphasis on the provision of community care and empowerment of MHCUs.[793] It states that,

- MHCUs should have access to care to the places where they live and work
- MHCUs should be provided with the least restrictive forms of care
- Local community-based resources should be mobilised wherever possible
- All avenues for outpatient and community based residential care should be explored before inpatient care is undertaken
- A recovery model with an emphasis on psychosocial rehabilitation should underpin all community-based services

In addition, the Policy recognises that recovery should focus on service development and delivery to build user capacity to return to, sustain and participate in satisfying roles of their choice in their community.[794] It also focuses on scaling up community-based mental health services before downscaling of mental hospitals by providing community residential care (including assisted living and group home); day care services; and outpatients services.[795]

Indeed, the NMHPFSP in its entirety presents a comprehensive government aspiration and intervention strategy for realising the right to mental health for all South Africans, with particular interest in provision of community-based mental health care to promote community inclusion and productivity of PWMDs.[796] The undertakings in the NMHPFSP demonstrate a clear preference for community-based mental health care and independent living rather than institutionalisation. The stipulations in the Policy are vital steps in adopting measures to enhance CMHCS and ensuring an effective

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[792] NMHPFSP, at 19.
[793] *Ibid*, at 20.
[794] *Ibid*.
[795] *Ibid*, at 23.
[796] SAHRC Report, 'Investigating the Status of Mental Health', at 23.

process of deinstitutionalisation and realisation of the right to independent living and community inclusion for PWMDs in South Africa. Hence, Uganda must 'borrow a leaf' from the South African policymakers and develop a mental health policy that emphasizes provision of CMHCS and support services to PWMDs and their families or caregivers.

The fundamental question is the variation between the rhetoric and the reality. The SAHRC reported that despite the fact that the NMHPRSP was lauded as a significant step forward in the mental health landscape, its progress has been inconsistent and implementation has been challenging.[797] The implementation of the Policy and provision of community-based mental health care remains wanting in South Africa.[798] In addition, the practical realisation of the right to community inclusion for PWMDs is also still far from meeting the aspirations of the Policy and the UNCRPD.[799] It is therefore hoped that the NMHPRSP will be reviewed and its gains— particularly with the provision of integrated health services and community mental health care—actualised to achieve its objectives and enable independent living and community inclusion of PWMDs.

5.1.4 White Paper on the Rights of Persons with Disabilities

The WPRPWDs, also referred to as the National Disability Rights Policy, was approved by the South African cabinet in 2015. It seeks to incorporate the provisions of the UNCRPD into the national framework.[800] Its vision is 'South Africa- A free and just society inclusive of all persons with disabilities as equal citizens'.[801] It employs the social and human rights models of disability and recognises that disability mainstreaming in both public and private life requires the removal of

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[797] *Ibid*, at 23.
[798] Lund and Flisher, 'A model for CMHCS in South Africa', at 1041; MHaPP, 'Promoting community-based services for mental health in South Africa', at 2.
[799] Mckenzie, Mcconkey and Adnams, 'Residential facilities', at 53.
[800] SAHRC Report, 'Investigating Mental Health in South Africa', at 24.
[801] MOSD, 'WRPWDs', at 42. A White Paper is a document that usually informs the public about a government's stand, programmes, policies and action on a particular subject matter.

barriers that hinder the participation of PWDs in society.[802] It comprehensively emphasizes empowerment as a core cross-cutting theme for enabling PWDs to avail of or access all social-economic development opportunities and rights that exist. It defines empowerment as,

> processes, procedures and actions aimed at affording access, equal treatment, inclusion, participation, accountability and efficiencies. It is premised on encouraging and developing the skills of self-sufficiency, with a focus on eliminating the need for charity or welfare in individuals and groups. From a disability perspective this means empowering or developing the skills and abilities amongst PWDs, and/or their care givers to effectively communicate their social-economic needs to others in society, advocate and lobby for their needs to be met, represent themselves and actively participate in all decision-making processes on matters directly impacting on their lives.[803]

The White Paper regards inclusion as a universal human right and aims at embracing the diversity of all people irrespective of race, gender, disability or other differences. It focuses on ensuring equal access to opportunities and eliminating discrimination and intolerance for all. It is about a sense of belonging, feeling respected, valued for who you are, feeling a level of supportive energy and commitment from others so that you can best fully participate in society with no restrictions or limitations.[804] These perspectives in the White Paper augur well with the pursuit for independent living and community inclusion of PWMDs in society.

Remarkably, in addition to the rights stipulated in the Constitution, the WRPWDs also stipulates a number of other rights to be enjoyed by all PWDs, namely: political rights; social rights to promote social cohesion and enable PWDs live in barrier free environment within their communities; economic rights so the PWDs can participate in economic processes and activities and live a dignified and self-reliant life and achieve financial independence; cultural rights that ensure that

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[802] *Ibid*, at 5.
[803] *Ibid*, at 6.
[804] *Ibid*, at 8.

PWDs enjoy their culture in conditions of equality, dignity and non-discrimination.[805]

In realising its objectives, the WRPWDs is premised on three main strategic approaches; that is, the Rights-based Approach,[806] Mainstreaming Approach,[807] and Life-Cycle Approach.[808] It further lays down nine pillars upon which it rests to guide the implementation and realisation of its vision. The pillars that are vital to enable promotion of community inclusion include: removing barriers to access and participation; protecting the rights of persons at risk of compounded marginalisation; supporting sustainable integrated community life; promoting and supporting empowerment of PWDs.

Certainly, the actualisation of these pillars and creation of an enabling environment are vital ingredients that propel PWMDs to flourish in society, and with the necessary support enjoy their right to independent living and community inclusion.

Unfortunately, despite the rhetoric of the policy documents, the SAHRC notes that,

> Various challenges impede the progress on the implementation of the White Paper including: inability of PWDs to access their rights on an equal basis with others; capacity challenges and lack of accurate data to inform programming, lack of inter-departmental coordination, lack of

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[805] *Ibid*, at 30-26.

[806] This provides a set of performance standards against which Government and other actors can be held accountable for the provision of all human, social and economic rights. It reinforces human rights principles such as universality, inalienable, indivisibility, equality and non-discrimination as the central core in the formulation.

[807] Disability mainstreaming involves and is centred on ensuring that disability is at the centre of all development initiatives as a norm and undisputed principle: that all budgets, policies, plans and programmes address the individual needs of PWDs; and the implication for PWDs of any planned actions, including legislation, policies and programmes is assessed.

[808] This approach commences at gestation, to the provision of social-economic services to PWDs. That is, all efforts must be made to integrate services and collaborate on its delivery so that all PWDs in a particular geographic space or living with a particular type of impairment are receiving an equitable service. This approach also requires that services provided to a child should continue as a child progress through various stages of his/her life, including when he/she is living as an older person.

accountability and redress mechanisms and need for increased support to civil society.[809]

It is imperative that these challenges are addressed by the South African government in order to breathe life into the laudable aspirations of the WPRPWDs.

5.1.5 Social Assistance Act (SAA)No. 13 of 2004

South Africa enacted this law to regulate access to and management of social assistance. The SAA spells out the different grants provided by the South African government.[810] The objectives of the Act include: the administration of social assistance and payment of social grants; to make provision for social assistance and to determine the qualification requirements; ensure the minimum norms and standards are prescribed for the delivery of social assistance; and to provide for the establishment of social assistance.[811] In addition, the Act provides for a number of social assistance grants, including: child support grants,[812] child dependency grants,[813] foster child grants,[814] disability grants,[815] older persons' grants,[816] war veterans' grants,[817] and a grant-in-aid.[818] The Act spells out the conditions of eligibility of the respective grants,[819] and provides for an Inspectorate of Grants.[820]

Eligibility to the disability grant requires the applicant to have attained the prescribed age, and, owing to a physical or mental disability, is unfit to obtain by virtue of any services, any employment or profession, the necessary means to provide for his or her maintenance. In addition, a person with a form of physical or

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[809] SAHRC Report, 'Investigating Mental Health in South Africa', at 24.
[810] Social Assistance Act No. 13 of 2004. From its long title, the Act is intended to provide for the rendering of social assistance to persons; to provide for the mechanism of rendering social assistance, among others.
[811] Section 3.
[812] Section 4(a).
[813] Section 4(b).
[814] Section 4(c).
[815] Section 4(d).
[816] Section 4(e).
[817] Section 4(f).
[818] Section 4(g).
[819] Section 5.
[820] Section 24-27.

mental condition that requires him/ her to be cared for by another person is eligible for Grant-in Aid.[821]

Although Uganda has a disability grant managed by the Ministry of Gender Labour and Social Development, there is no statutory law providing for it, as is the case in South Africa. The existence of the South African Act is commendable. Its impact with respect to the disability grant will be discussed later.

The South African government's commitment to disability rights as stipulated in the Constitution, the WPRPWDs, the PEPUDA, the NMHPFSP, the MHCA 2002 and the Social Assistance Act, among other policies,[822] which seek to secure better protection and inclusion of all PWDs in South Africa, is enviable. Notably, unlike South Africa, Uganda has no mental health policy save for the MHA 2019. The NMHPRSP and the WPRPWDs provide good models for Uganda, especially in terms of their emphasis on community-based mental health care, comprehensive empowerment of PWDs and elimination of environmental barriers to promote social integration and productivity of all PWDs. Hence, Uganda ought to adopt both a mental health policy as well as design and implement measures and programmes to promote provision of CMHCS and support services, and ensure an enabling environment for PWMDs. These strategies are necessary for the realisation of deinstitutionalisation and the right to independent living and community inclusion for PWMDs. Importantly, these interventions must involve consultation with PWMDs, their caregivers and families, as well as DPOs.

Notwithstanding the celebrated reforms presented in the South African legal and policy frameworks in the mental health sector, there still exist challenges that inhibit the realisation of the objectives of the legal and policy regime. These include: limited funding of psychiatric hospitals; lack of specialised psychiatric services;

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[821] Section 12.
[822] The Policy on the Provision of Social Development Services for Persons with Disabilities 2017; The Policy on Residential Facilities; The Policy on Protective Workshops; The Policy Guidelines on Recipe Care.

limited staff numbers coupled with limited competencies of the existing staff; inadequate facilities and difficulty of managing severe mental health patients with other medically ill patients in general wards; increased burden to families caring for mental health users without adequate support provided to the families; and an inadequate system of community-based psychiatric services.[823] These challenges clearly confirm that, progressive laws alone are not the magic bullet to improve mental health care by the State. The government must also take additional pragmatic and programmatic measures to address these challenges. Key among the measures include: increasing budgetary allocation to the sector; providing integrated health services and a comprehensive community-based mental health care and support services for PWMDs; increasing competent human resource; ensuring availability of medication and support services; providing support to families with PWMDs, as well as enhancing access to accurate information regarding availability of government supports and intervention.[824] These measures will improve access to mental health care at all levels, as well as reduce institutionalisation of PWMDs to only the severe cases, which must be managed in the least restrictive environment and for the shortest period. These are essential pillars for the realisation of the right to independent living and community inclusion for PWMDs.

The next section examines the efficacy of the current programmatic intervention undertaken by the South African government to meet its aspirations to promote community living and inclusion for PWMD.

5.2. Support initiatives to promote independent living and community inclusion in South Africa

Independent living, according to the WPRPWDs, is the ability of a PWD to live just like anyone else, to have opportunities to make decisions that affect their lives,

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[823] Simpson and Chipps, 'Mental Health Legislation in South Africa', at 55; Szabo and Kaliski, 'A South African Perspective', at 70; Lund, Kleintjeis *et al,* 'Challenges Facing the South African Mental Health Systems'; Jack-Ide *et al*, 'Comparative study of mental health care', at 53.

[824] Ramlall, 'Trials and Triumphs,' at 410; Burns, 'The Mental Health Gap in South Africa-A Human Rights Issue', at 100.

and to be able to pursue activities of their own choosing with necessary support to enable all PWDs to live independently.[825] In its third Pillar, the WPRPWDs calls for supporting sustainable community life. It recognises that PWDs have an equal right to live in the community, with choices equal to others. This requires that government across all spheres, designs and undertakes effective and appropriate measures to facilitate the full enjoyment by PWDs of their rights and their full inclusion and participation in the community.[826]

However, despite this commitment, South Africa in its initial report to the UNCRPD Committee admitted that it lacks sufficiently structured and co-ordinated provision of community-based support services to PWDs to create a conducive inclusive environment.[827] In its Concluding Observations, the UNCRPD Committee has urged South Africa to, among others:

> Adopt an action plan at all levels to develop community support services in urban and rural areas including: providing personal assistance, grants and support to families of children with disabilities and parents with disabilities, covering support for assistive devices, guides and sign language interpreters.[828]

This section examines the strategies that have been instituted by South Africa to empower PWMDs to realise the right to independent living and community inclusion as enshrined in Article 19 and 14 of the UNCRPD and the ADP respectively.

a) Provision of supported mental health care residential facilities

The Ubuntu Association contends that PWMDs in South Africa are restricted in their right to live independently and be included in the community, including the

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[825] MOSD: WRPWDs, at 9.
[826] *Ibid.*, at 70.
[827] Department of Women, Children and Persons with disabilities (DWCP), 'South Africa Baseline Country Report,' at 310.
[828] UNCRPD Committee Concluding Observations on the Initial Report of South Africa,' at 9-10.

right to choose freely where and with whom they live.[829] Many are forced to live in institutions, residential and age-care facilities in order to receive social and personal care support or access to accessible housing and shelter.[830] This reality limits the options of PWMDs to exercise their housing rights, consequently violating the true essence of independent living and community inclusion.[831]

In its 2012 State Report to the UNCRPD Committee, South Africa reported that residential facilities were the alternative to institutionalisation in mental health facilities for PWMDs, and that there were approximately 7,982 PWDs (6,416 in urban and 1,566 in rural) living in the 149 residential facilities (101 urban, 19 peri-urban and 29 rural) in the country at the time. Residential facilities that are run by NGOs receive subsidisation from the State.[832] The report further revealed that government support towards supported or assisted living in smaller homes or units to pave way for deinstitutionalisation was very limited at the time.[833] However, it should be noted that residential care facilities, though smaller in size, may still qualify as institutions and perpetuate institutionalisation of PWMDs if not well run to ensure that PWMDs retain their right to choice and personal autonomy, support and inclusion.[834]

Section 26 of the South African Constitution recognises the right to adequate housing for all persons and places a duty on the State to progressively realise this right.[835] Notably, the National Housing Act makes no special guarantee for the provision of sustainable and adequate housing for PWDs.[836] In comparison,

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[829] The Ubuntu Centre, Submissions to the Committee on the Rights of Persons with Disabilities: List of Issues (South Africa) to be adopted during the 18th Session of the Committee on the Rights of Persons with Disabilities', at 14.
[830] *Ibid*, at 14.
[831] Inclusion International, 'Global report on Article 19', at 64.
[832] DWCP, 'South African Baseline Country Report', at 31-32.
[833] *Ibid*, at 31-32.
[834] Inclusion International, 'Global report on Article 19', at 64.
[835] Section 26.
[836] The National Housing Act No. 107, 1997.

Uganda's 1995 Constitution has no express stipulation on the right to housing. However, Objective XIV of the NODPSP enjoins the State to:

> Endeavour to fulfil the fundamental rights of all Ugandans to social justice and economic development and shall in particular ensure that all Ugandans enjoy the rights and opportunities and access to decent shelter among others.[837]

Furthermore, the Ugandan National Housing and Construction Corporation (NHCC) Act Cap 313 largely focuses on the establishment of the National Housing and Construction Corporation with the mandate to develop, build, manage or sell houses on behalf of the government.[838] Interestingly, the NCCA mandates the Corporation to provide or assist in providing housing accommodation for citizens of Uganda at an economical cost.[839] Similar to the South African context, the right to housing for PWDs is not addressed specifically, hence the need for both States to amend their respective laws to take cognisance of and address the unique housing needs for PWDs generally.

b) Community Based Rehabilitation (CBR)

According to the South African WPRPWD, CBR is a strategy to enhance the quality of life of PWDs through rehabilitation and habilitation, equalisation of opportunities, poverty-reduction and social inclusion.[840] Unfortunately, there are very limited efforts towards CBR in South Africa, with efforts only being undertaken in two Provinces in the country with the support of NGOs.[841] The SAHRC observes that due to the limited availability of CBR and CMHCS, the medical model of hospitalisation in inadequately facilitated and poor facilities is still the primary practice with no or limited community-based services.[842] However, CBR and mental

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[837] NODPSP, Objective XIV(b).
[838] NHCC, Sections 2 and 3.
[839] *Ibid,* Section 3(2).
[840] WPRPWD at 4; Notably, Article 19 of the UNCRPD and 14 of the ADP adopt the term Community-based Support Services.
[841]DWCP, 'South Africa Baseline Report to the UNCRPD', at 32.
[842]SAHRC Report, 'Investigating Mental Health in South Africa', at 31-32; WHO, 'AIMS Report on Mental Health Systems in South Africa', at 26.

health care is essential to ensure that PWMDs can live fruitful lives in their communities.

In Uganda, although there is a CBR strategy implemented by the MGLSD to improve the livelihood, empowerment and inclusion of PWDs, its services and impact has not reached PWMDs. It is imperative therefore, that both States develop CBR models that identify and address the unique needs of the various categories of disabilities so as to ensure equity and comprehensive social transformation.

c) Disability Grant under the Social Assistance Act

The disability grant recipients are those who require full-time care by another person owing to their physical or mental disability.[843] A permanent disability grant is applied for where the disability will continue for more than one year. A temporary disability grant applies where the disability will continue for more than six months but less than one year.[844] According to the South African Social Security Agency (SASSA), a successful applicant for a disability grant will receive 1,860 Rands monthly;[845] an applicant for care dependency grant meant for a child with disabilities can receive 1,860 Rands monthly;[846] and an applicant for Grant-in-Aid meant to assist the person who takes care of a person who cannot care for oneself receives 450 Rands monthly.[847] However, these amounts have been revised due to the Covid-19 economic realities. A Special Covid-19 Social Relief Distress Grant of R350 monthly was introduced in the country; child support grant beneficiaries were allocated an additional R500 monthly; and an extra R250 was added to the disability grant and Grant-in Aid.[848]

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[843] Section 9 of the Social Assistance Act; DWCP South Africa Baseline Report to UNCRPD, at 31-32.
[844] South African Social Security Agency (SASSA), 'Disability grant'.
[845] *Ibid.*
[846] *Ibid.*
[847] *Ibid.*
[848] https://www.gov.za/covid-19/individuals-and-households/social-grants-coronavirus-covid-19?gclid=Cj0KCQjw6NmHBhD2ARIsAI3hrM0qfYvduqsdCM08dAzy49vTOjZdFz1SSEsMbxA3V6t8_QyhT5Cd6qYaAjcjEALw_wcB (Accessed on 19th July 2021).

However, although the disability grant is available for all persons in both rural and urban areas, the requirement of a report from a medical practitioner inhibits many PWDs from accessing the grants.[849] There is no information or disaggregated data regarding the extent of access by and benefit of these grants to PWMDs specifically.

d) Supported employment initiatives

The State report also revealed a number of supported or subsidised employment initiatives to support PWDs in light of the high unemployment rates in the country. These initiatives include:[850]

- Sheltered work: This is work undertaken by PWDs in workshops specifically established for that purpose. Here, people receive the applicable government grant plus an additional weekly payment. There are currently 12 of these workshops in Gauteng, Western Cape, North West, Eastern Cape, Northern Cape, Free State and KwaZulu Natal, all situated in urban centres, employing 926 persons with disabilities.[851]
- Integrative enterprises: These are workshops paying normal wages.
- Supported employment: A system of support for PWDs in respect of ongoing employment in integrated settings.
- Open labour markets
- Protective workshops: These are mainly run by NGOs of PWDs but subsidized by government through the Department of Social Development (DOSD). By 2012, 293 protective workshops providing household income for 14,212 persons with disabilities were subsidised. This was an increase from 260 protective workshops benefiting 6,585 beneficiaries subsidised in 2010.[852]

[849] Jelsma, Eide and Maart, 'Disability grant in South Africa', at 1145.
[850] DWCP, 'South African Baseline State Report', at 58.
[851] *Ibid*, at 59.
[852] *Ibid*.

Unfortunately, these initiatives are largely situated in the urban areas, and yet most of the PWDs are in the rural areas, and hindered by lack of education, unemployment, high cost of transportation are unable to access the initiatives and to benefit from them.[853] Furthermore, there is no information regarding the extent of inclusion of PWMDs in these supported employment initiatives.

e) Tax exemptions for PWDs

The South African Baseline report also reported that there are tax exemptions allowed on a number of expenses for PWDs such as: medical expenses, transport costs especially for learners with disabilities, purchase and maintenance of assistive devices, assistive limbs and technology required to enable PWDs to perform their daily activities.[854] It is hoped that PWMDs can also benefit from this tax exemption for any unique assistive device that they may require to support their independent living and community inclusion.

From the foregoing analysis, it is clearly evident that like Uganda, South Africa is struggling with its efforts toward providing adequate and quality mental health care and support to its populace with mental disabilities. Progressive laws and policies that favour protection and promotion of rights of PWMDs exist, as well as efforts towards deinstitutionalisation and support initiatives. However, they are insubstantial in addressing the need for community-based mental health care and support services to enable PWMDs' independent living and community inclusion. Arguably, the initiatives adopted by South Africa, though commendable, are inadequate and not specifically tailored to address the unique needs of PWMDs to support their independent living, participation and community inclusion. There is also a paucity of information regarding the number of PWMDs who have accessed and benefited from the initiatives. In fact, the SAHRC has noted that beyond the

[853] *Ibid*, at 80-81.
[854] *Ibid*, at 63.

rhetoric, South Africa requires substantial progress to be made on numerous fronts in order for the country to meet its obligations in terms of the UNCRPD.[855] The UNCRPD Committee has also called on South Africa to design a National Strategic and Legislative Framework for deinstitutionalisation of PWDs, including: all the necessary independent living community support services, and to ensure that PWDs are effectively included through their representative organisation at all stages of deinstitutionalisation.[856] As such, it can be concluded that South Africa needs to also identify strategies or models that will promote the provision of CMHC as well as the realisation of the right to independent living and community inclusion for PWMDs to meet the aspirations of the UNCRPD and the ADP.

That said, Uganda can learn from the current South African strategies and remodel them to ensure access, availability and benefit to all PWDs, with specific reasonable accommodations for those with mental disabilities.

5.3 KENYA

5.3.1 The State of Mental health and Institutionalisation of PWMDs in Kenya

Kenya borders Uganda to the East and is a member of the East African Community (EAC). The recent 2019 census report reveals that Kenya's population stood at 47.6 million people,[857] of which 23,548, 056 were males, 24,014,716 females and 1,524 intersex.[858] Using the UN-Washington Group of Questions for data collection to determine disability prevalence among persons of five years and above, the 2019 census revealed that 2.2% (that is, 0.9 million) of Kenyans live with some form of disability. Of the Kenyan population, 1.9% of men and 2.5% of women have a disability. Further, 2.6% (0.7 million) of PWDs live in rural areas and 1.4% (0.2

[855] SAHRC Report, 'Investigating Mental Health South Africa,' at 56.
[856] UNCRPD Committee, Concluding Observation to Initial Report of South Africa', at 9-10.
[857]Kenya National Bureau of Statistics, 'Kenya Population and Housing Census Volume 11 (2019): Distribution of Population by Administrative Units', at 1.
[858] *Ibid*, at 10.

million) in urban areas.[859] There are more people with mobility disabilities at 42% (0.4 million), other form of disability including sight, hearing, cognition, self-care and communication are experienced by 36% and 12%, of which cognition constitutes about 200,000 people.[860]

PWDs in Kenya continue to face stigma, discrimination, marginalisation and varying human rights challenges.[861] Entrenched societal stereotypes portray PWDs as burdens and curses, and in some instances, individuals and families with PWDs have shied away from revealing such persons.[862] Besides, some PWMDs who are not institutionalised or abandoned and neglected depend on their families for social, financial, material and psychological support.[863] As a result of this dependency, PWDs are still viewed as persons without equal rights, but mere recipients of care, with no rights to make decisions about their lives on their own, which should rather be made by their families.[864]

Specific to PWMDs, the UNCRPD Committee disparaged the state of discrimination and stigmatisation [and institutionalisation] of persons with psychosocial and intellectual disabilities that disproportionately affects their access to education, health and employment.[865] The Kenya Mental Health Policy (KMHP) similarly notes that PWMDs often have their human rights violated, and may also be subjected to unhygienic and inhumane living conditions, physical and sexual abuse, neglect as well as harmful and degrading treatment and practices in health facilities.[866] As a result of the discrimination and stigma, PWMDs live under cover and are typically considered dangerous to themselves and others, resulting in

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[859] Development Initiatives, 'Status of Disability in Kenya', at 6.
[860] *Ibid*, at 7.
[861] Kabare, 'Social Protection', at 10.
[862] Kenya National Report, 'Kenya's Initial State Report Article 35(1)', at 13.
[863] *Ibid*, at 8.
[864]Kenya National Commission on Human Rights (KNCHR) and Open Society Initiative for Eastern Africa (OSIEA), 'How to Implement Article 12', at 83; Users and Survivors of Psychiatry-Kenya (USPK), 'A Day of General Discussions on Article 19 of the UNCRPD', at 5.
[865]UNCRPD Committee, 'Concluding Observations in relation to the Initial Report of Kenya', para 15-16.
[866] Kenya Mental Health Policy (KMHP), 'Highest Standard of Mental Health', at 2.

exclusion from mainstream society and denial of the right to make decisions or live independently like other people.[867]

With respect to the state of mental health care, mental health conditions contribute significantly to disease burden in Kenya.[868] Although there is no reliable data on the prevalence of mental disorders in Kenya, it has been estimated that up to 25% of out-patients and 40% of in-patients in health facilities suffer from mental health conditions such as depression, post-traumatic stress disorder, panic disorder, generalised anxiety disorder, alcohol dependency or obsessive compulsive disorder.[869] Ndetei, Khasakhala, Kuria *et al* report that the mental illness is fairly common in Kenya with a prevalence rate of 40% for those in medical or general wards.[870] Despite this, there is a glaring gap between mental health care needs and the available services. Furthermore, while the actual numbers cannot be ascertained, persons with psychosocial disabilities are often institutionalised in various mental hospitals in Kenya due to lack of an alternative mode of medical intervention.[871] Like in Uganda, those not institutionalised become homeless or live with their families for care and support even throughout adulthood.[872]

Kenya has only 500 mental health professionals, and also suffers from inadequate funding and underdeveloped policy frameworks.[873] These factors add to the challenges of delivering broad population-based mental health care.[874] Similarly, Kiima and Jenkins note that mental health care systems in Kenya operate under extremely resource-restricted conditions in terms of infrastructure, limited staffing and finances. Mental health specialist care and services are largely delivered at both district and provincial level by psychiatrist nurses running out-patient clinics, and

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[867] Amboko, 'Right to Legal Capacity', at 17, 25.
[868] KNCHR, 'Silenced Minds', at 17.
[869] Ibid, at 18.
[870] Ndetei, Khasakhala, Kuria *et al*, 'Mental Disorder in at Adults', at 1.
[871] USPK, 'A Day of General Discussions on Article 19 of the UNCRPD', at 2.
[872] Ibid, at 5.
[873] Marangu, Sands, Rolley, *et al*, 'Mental healthcare care in Kenya', at 1.
[874] *Ibid*.

in-patient units, and by the national referral hospital at Mathari Hospital, Gill hospital and Moi University.[875]

According to KNCHR findings, 70% percent of the beds available in public facilities are located in the country capital, Nairobi. The total number of public hospital beds for a population of nearly 50 million is 1114: 750 at Mathari Hospital; 40 beds at MTRH; 100 beds at Gill; 6 provincial units of 22 beds each at Nakuru (Rift Valley), Kisumu (Nyanza), Nyere (Central), Embu (Eastern), Port Reitz (Coast), and Kakamega (Western); and only 5 district Units (Machakos 22 beds; Isiolo 10 beds; Kerugoya, 20 beds; Muranga, 20 beds; Meru 12 beds and Siaya 8 beds. Hence, there are only 22 public beds for a population of 4 million in most provinces, which translates into a ratio of 1 bed per 200,000 population.[876] Furthermore, the KNCHR also reports that in 2009 there were 46 psychiatrists in the public service, of which 28 were based in Nairobi. There are also varying differences in the distribution of the psychiatrists across Kenya, with 12 of those available for the 10 million population in Nairobi and only 2-3 psychiatrists available to attend to a similar number outside the country's capital.[877] In addition, of the 418 trained psychiatric nurses in Kenya, only 250 are deployed in psychiatry. Of these, 70 are based in Mathari Hospital, leaving only 180 in the rest of the districts and provinces.[878] Besides the limited human resources and inaccessible services, is the general poor state of the mental health facilities. Findings of the KNCHR reveal the deplorable state of Mathari Hospital which has old, unhygienic and dilapidated 'prison-like' buildings which make it unconducive for the objectives of the institution.[879]

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[875] Kiima and Jenkins, 'Mental Health Policy in Kenya', at 4.
[876]KNCHR Report, 'Silenced Minds', at 30.
[877]*Ibid*, at 30.
[878]*Ibid,* at 31.
[879]*Ibid*, at 32-34; Also see, CNN, *The World's Untold Stories: Locked up and Forgotten*; Judith Klein, 'The Other Side of Kenya's terrible Secret Voices,'(2011).

Furthermore, societal stigma and discrimination even by medical practitioners and politicians compound the challenges faced by PWMDs in Kenya.[880] The KNCHR mental health human rights audit confirmed that as a consequence of stigma and discrimination, mental health has been given a low priority by politicians and policy makers, thus hindering the realisation of the right to the highest attainable standard of mental health.[881] Furthermore, due to the stigma within the family, PWMDs are often taken to far off facilities to conceal the information about their mental health from being known in the community, and those who have undergone treatment are frequently abandoned upon discharge by their families.[882]

Evidently, the prevailing state of stigmatisation, discrimination and institutionalisation in deplorable mental health facilities with inadequate human and financial resources is not different from the situation in Uganda and South Africa as discussed above. To this end, the UNCRPD Committee's Concluding Observations made recommendations to Kenya to,[883]

> (a) Adopt a strategy for the de-institutionalisation of persons with disabilities, within a timeframe and measurable indicators. This strategy must involve the participation of organisations of persons with disabilities;
>
> (b) Launch a comprehensive strategy with timeframe and human rights-based indicators to provide for community-based services available for persons with disabilities; and
>
> (c) Take steps to introduce specific budgetary allocations, for the promotion of independent living, including cash transfer schemes for personal assistance services.

Furthermore, like Uganda and South Africa, Kenya's mental health sector is grappling amidst the existence of fairly progressive legal safeguards enshrined in the

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[880] Marangu, Sands, Rolley, *et al*, 'Mental healthcare care in Kenya', at 2; KNCHR Report: 'Silenced Minds', at 39; Paul Muchiri Karanja, 'Why Kenyans would rather take the mentally ill to a faith healer'.
[881] KNCHR Report, 'Silenced Minds', at 44.
[882] *Ibid*, at 38.
[883] UNCRPD, Concluding Observation CRPD/C/KEN/CO/1, para. 37-38.

international, regional and domestic legal frameworks that seek to promote and protect the rights of PWMDs in Kenya, as seen in the following section.

5.3.2 A Review of the Legal and Policy Framework on PWMDs in Kenya

Like Uganda and South Africa, Kenya has also ratified the UNCRPD.[884] But, like Uganda, it has neither signed, ratified nor acceded to the ADP. Commendably, through Article 2(6) of the Constitution of Kenya, 2010, the ratified UNCRPD forms part of the country's law.[885] In addition to the UNCRPD, Kenya like Uganda is also party to a number of other international and regional human rights instruments,[886]and has similarly adopted progressive national laws to guarantee and protect the rights of all PWDs.

This section reviews Kenya's legal and policy frameworks to ascertain the extent to which they provide for the provision of CMHC and guarantee the right to independent living and community inclusion for PWMDs.

5.3.2.1 The Constitution

The Constitution of Kenya[887] is the supreme law of the country and binds both State and non-State actors.[888] Like both Uganda and South Africa, the Constitution contains a Bill of Rights and provides the framework for social, economic and cultural policies passed in the democratic State.[889] It re-affirms that the purpose of recognising and protecting human rights and fundamental freedoms is to preserve the dignity of individuals and communities and to promote social justice and the realisation of the potential of all human beings.[890] The Constitution spells

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[884]Ratified the UNCRPD on 19th May 2008.
[885]Article 2(6) provides that 'Any treaty or convention ratified by Kenya shall form part of the law of Kenya under this Constitution'.
[886]Ratification/ Accession dates of various instruments: ICCPR on 1st May 1972: ICESCR: 1st May 1972: CEDAW: 9th March 1984; CAT: 21st February 1997: CRC: 30th July 1990: ACHPR: 23rd January 1992, among others.
[887] The Constitution of Kenya, 2010.
[888] Article 2(1) states that the Constitution is the supreme law of the Republic and binds all persons and State organs at all levels of government.
[889] Chapter Four of the Constitution and Article 19(1).
[890] Article 19(2). Also see, Article 20(2).

out various fundamental human rights and freedoms to be protected and enjoyed by all persons including PWDs, namely: the right to life;[891]equality before the law, equal protection and equal benefit of law;[892] and prohibition of direct or indirect discrimination of any persons on various grounds, including disability.[893] It guarantees the right of all persons to inherent dignity and the right to have that dignity respected and protected.[894] It protects the right to freedom and security of all persons and prohibits inter alia torture, physical or psychological violence cruel, inhumane and degrading treatment of all persons.[895]

Similar to Uganda and South Africa, the Kenyan Constitution also provides for specific protection for PWDs. Article 54(1) states that,

> A person with any disability is entitled,[896]
>
> a. to be treated with dignity and respect and to be addressed and referred to in a manner which is not demeaning
> b. to access educational institutions and facilities for persons with disabilities that are integrated into society to the extent compatible with the interests of the persons
> c. to reasonable access to all places, public transport and information
> d. to use of sign language, braille or other appropriate means of communication, and
> e. to access materials and devices to overcome constraints arising from the person's disability

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[891] Article 26.
[892] Article 27. Article 27(2) provides that equality includes the full and equal enjoyment of all rights and fundamental freedoms.
[893] Article 27(4).
[894] Article 28.
[895] Article 29(a-f).
[896] Article 260 of the Constitution defines 'disability' to include 'any physical, sensory, mental, psychological or other impairment, condition or illness that has, or is perceived by significant sector of the community to have, a substantial or long-term effect on an individual's ability to carry out ordinary day-to-day activities.' Unfortunately, the definition is limited. It focuses on the persons impairment alone, that is, the medical model, and does not embrace the social model of disability to recognise the environmental factor.

Although Article 54 makes no reference to CMHCS, provision of community support services and promoting community inclusion for all PWDs, it is still commendable for a number of reasons. First, it protects 'any' PWD, including those with mental disabilities; secondly, the specific wording of the entitlement to PWDs is intended to facilitate programmatic interventions as well as promote inclusion; and thirdly, it can be utilised purposively to promote independent living and community inclusion of PWMDs in society.

In addition to providing for the fundamental rights and freedoms, the Constitution places a duty on all State organs and public officers to address the needs of vulnerable groups within the society, including PWDs.[897] This is very important as it gives the populace the mandate to hold State actors accountable to the citizenry for any actions or omissions contrary to the guarantees in the Bill of Rights.[898]

In addition, the Kenyan National Human Rights and Equality Commission (KNHEC)[899] is mandated to engage in monitoring, investigating, conducting research and hearing complaints for alleged human rights violations.[900] Its quasi-judicial function is similar to the Uganda Human Rights Commission[901] and the Equal Opportunities Commission,[902] as well as the South African Equality Court.[903] The KNHEC provides another cost-effective and accessible forum for the protection of the rights of PWMDs in Kenya and for holding the perpetrators of human rights abuses accountable. Access to justice is one of the key tenets of independent living and community inclusion.

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[897] Article 21(3).
[898] Articles 22 and 23 permit any person or organisation to institute court proceedings when a right stipulated in the bill of rights has been denied, violated or infringed upon or is threatened and to a grant of appropriate redress.
[899] Formerly the Kenyan National Commission on Human Rights.
[900] Part 5, Article 59.
[901]Established under Article 54 of the 1995 Constitution.
[902] Established under Article 32 and by the Equal Opportunities Act 2007.
[903] Section 16- 23 of the PEPUDA.

5.3.2.2 Persons with Disabilities Act No.14 of 2003[904]

The Kenyan PWDA was enacted prior to the country's adoption of the 2010 Constitution and also prior to its ratification of the UNCRPD. The PWDA seeks to provide for the rights and rehabilitation of all PWDs; to achieve equalisation of opportunities for all PWDs; and to establish the National Council for Persons with Disabilities.[905] Focused largely on the medical model, the Act defines 'disability' as:

> a physical, sensory, mental or other impairment including any visual, hearing, learning, or physical incapability, which impacts adversely on social, economic or environmental participation.[906]

This definition clearly departs from the one stipulated in the UNCRPD, ADP and Uganda's PWD Act, 2020 that incorporate both the medical and the social model of disability by recognising both the impairment and the environmental barriers.

Despite this shortcoming, the Kenyan PWDA remarkably sets out a number of other rights and privileges that are buttressed by the Constitution and are pertinent to the realisation of the right to independent living and community inclusion. These include: the right to access suitable employment;[907] the right to non-discrimination in employment;[908] the right to education for all PWDs and the adoption of special needs for learners with disabilities;[909] the right to health;[910] and the right to a barrier free and disability-friendly environment to ease accessibility and mobility.[911]

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[904] This Act is currently under review through the Persons with Disabilities (Amendment) Bill (2019) which, among others, spells out the obligations of both the National and County governments in promoting and protecting disability rights.
[905] See the Long title to the Act.
[906] Section 2.
[907] Section 12. Also see, section 13 on Reservation of employment quotas and section 14 on Apprenticeship.
[908] Section 15. Also see, section 16 on incentives of tax reduction to employers who employ PWDs.
[909] Section 18 and 19.
[910] Section 20.
[911] Section 21. Also see, section 22 on access to public buildings; section 23 on accessible public vehicles, and section 24 on adjustment orders.

Unlike similar Acts in Uganda and South Africa, the Kenyan PWDA provides for the establishment of a National Development Fund for Persons with Disabilities.[912] This is significant as PWMDs are reported to be the most marginalised, unemployed and face abject poverty. Hence, the availability and accessibility of these funds by PWMDs is material in alleviating the poverty levels, enabling acquisition of any required device, ensuring access to desired services and inclusion in the community.

To combat exclusion, discrimination and marginalisation, the Act makes it an offence for any person to conceal a PWD and deny him or her access to opportunities. Section 45 stipulates that:

1. No parent, guardian or next of kin shall conceal any person with a disability in such a manner as to deny such a person the opportunities and services available under this Act.
2. A person who contravenes sub-section (1) is guilty of an offence and on conviction is liable to a fine not exceeding twenty -thousand shilling.

This provision is crucial, particularly for PWMDs, who as reported earlier are frequently excluded or isolated by both the community as well as their families.[913] Effective implementation of this provision in regard to PWMDs, will hopefully curtail the negative stereotypes in society that lead to isolation, concealment, discrimination and marginalisation, and will enhance access to social services, including CMHCS when availed by PWMDs. It may also enable community inclusion and lead to the achievement of the desired attitudinal and social transformation in the society.

It is noteworthy that the Kenyan PWDA is supported by a number of regulations including the Person with Disabilities (Cost, Care, Support and Maintenance) Regulations 2009. These regulations have several applaudable

[912] Sections 32(2) and 33-34.
[913] KNCHR, 'Silenced Minds', at 17.

guarantees including: the establishment of a council for persons with severe disabilities to support the development and implementation of community-based rehabilitation and welfare programmes of PWSDs; training in vocational and independent living skills for their inclusion in the communities; maintenance orders granted by the court in favour of PWSDs against their caregivers; provisions for access to housing loans and suitable houses; provision of unemployment allowances; and monthly allowance to parents or guardians who have children. However, the regulations also emphasize admission of persons with severe disabilities in institutions for care, with limited focus on provision of community-based mental health care.[914]

Certainly, the legal safeguards stipulated in the Kenyan PWDA apply to all PWDs. However, unique aspects for PWMDs are further covered under the Mental Health Act, 1989 discussed below.

5.3.2.3 Mental Health Act (Cap 248), 1989[915]

From its long title, the MHA was passed to amend and consolidate the laws relating to the care of persons who are suffering from mental disorder or 'mental subnormality' with mental disorder; for the custody of their person and the management of their estate; for the management and control of mental hospitals and for connected purposes.[916] Extolling the MHA, Ndetei, Muthike and Nandoya opined that it attempts to decentralise services, allows for the gazetting of any hospital as a mental health hospital, provides for shortened admission procedure and attempts to integrate mental health services within the nation's general health services.[917] Unfortunately, unlike Ugandan and South African legislation, the

[914] Regulation 3(1), 5,6 and 12.
[915] This MHC, 1989 was revised in 2012. It repealed the Mental Treatment Act of 1959 which was enacted during the colonial era.
[916] Long title to the Act.
[917] Ndetei, Muthike and Nandoya, 'Kenya's Mental Health Law', at 96.

Kenyan Act makes no reference to the protection of fundamental rights and freedoms of PWMDs or the provision of CMHC and support services.[918]

Institutionalisation of PWMDs in Kenya is the dominant mode of care due to lack of alternative modes of medical interventions.[919] While critiquing the MHA, Ndetei, Muthike and Nandoya noted that,

> The main shortcoming of MHA is its over-emphasis on in-patient treatment. Although it offers some protection for in-patients regarding ill treatment in hospital, administration of their estates and examination of females, it fails to address the patient's rights to information, consent to treatment, confidentiality and conditions in mental health facilities.... Further it does little to promote community mental health services at the primary care level and makes no distinction between mental illness and mental disability.[920]

In addition, the Kenya National Commission on Human Rights (KNCHR) has also identified the need for government to address the systemic neglect of the mental health sector, embark on policy and legislative reform, ensure improved budgetary allocations to the sector, as well as deepen its provision of mental health care and support at community and primary levels.[921] Notably, the UNCRPD Committee also expressed its concerns with the continued practice of institutionalisation and urged the Kenyan government to amend its MHA to shift from placing emphasis on institutionalised care or involuntary admissions care to provision of community-based mental health care and services.[922]

However, like Uganda's MHA 2019, the Kenyan MHA, 1989 still presents a number of positive changes as set out below:

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[918] *Ibid*, at 96; KNCHR Report, 'Silenced Minds', at 19-20.
[919] USPK, 'Article 19 of the UNCRPD', at 2.
[920] Ndetei, Muthike and Nandoya, 'Kenya's Mental Health Law', at 96.
[921]KNCHR, 'Silenced Minds', at 45.
[922] UNCRPD Committee, Concluding Observations CRPD/C/KEN/CO/1: para. 5, 6, 28 and 37.

a) Use of non-derogative language

Moving away from the use of derogative language such as 'unsound mind', the Act defines a person with a mental disorder as:

> a person who has been found to be so suffering under this Act and includes a person diagnosed as a psychopathic person with mental illness and a person suffering from mental impairment due to alcohol and substance abuse.[923]

This definition is narrow compared to that stipulated in the Ugandan MHA 2019, which encompasses various forms of mental illness and substance abuse. Further, although the use of the term 'mental disorder' and 'suffering' still connotes pain within the medical lens of disability, the use of non-derogative terminology is laudable.

b) Establishment of the Mental Health Board

Similar to the MHA, 2019 and MHCA, 2002 of Uganda and South Africa respectively, the Kenyan MHA, 1989 provides for the Kenya Mental Health Board whose functions are to: co-ordinate the mental health care activities in Kenya; advise the Government on the state of mental health and mental health care facilities; approve the establishment of mental hospitals; inspect mental hospitals and ensure that they meet the prescribed standards; assist whenever necessary in the administration of any mental hospital; receive and investigate any matter referred to it by a patient or relative of a patient concerning the treatment of the patient at a mental hospital and where necessary to take or recommend to the minister the appropriate remedial action; advise government on the care of persons suffering from 'mental subnormality' without mental disorder; initiate and organise community or family based programmes for the care of persons suffering from

[923] Section 2.

mental disorder and perform such other functions that may be conferred upon it by law.[924]

By giving the Board powers to investigate any complaints brought by the patients or the patient's relative regarding treatment of the PWMDs in the mental facility, the Act impressively creates an avenue for holding perpetrators accountable and granting redress to victims of any form of human rights abuse. It also paves way for the Board's adoption of community-based programmes that are relevant to the promotion of independent living and community inclusion of PWMDs. It is indubitable that the applauded functions of the Board, if well executed, could tremendously enhance the protection of the rights of PWMDs in Kenya and promote community inclusion.

Unfortunately, the Kenya National Commission on Human Rights report revealed that the Board has a number of shortcomings. These include: the Board's exclusion from participation in mental health policy and programme development; lack of transparency and independent oversight of service providers; limited avenues for patients to lodge complaints due to inaccessibility and gross under-funding, which has greatly curtailed its ability to perform its mandate.[925] Therefore, it is imperative that these shortcomings are addressed to enable the Board to effectively exercise its mandate. Uganda, on the other hand, must learn that upon constitution of its Mental Health Advisory Board, adequate funding of the Board and accessibility by PWMDs or their caregivers are vital factors in actualising the Board's functions.

c) Recognition of the role of the family

Similar to the Ugandan and South African mental health legislation, the Kenyan MHA, 1989 also provides for the different circumstances of admission of PWMDs in the mental facility, as well as the time limitation for those admitted to a facility to

[924] Section 5.
[925] KNCHR report, 'Silenced Minds', at 22.

avoid long-stay institutionalisation. These circumstances include: voluntary admission;[926] Involuntary admissions;[927]and emergency admission.[928] In addition, the MHA, 1989 also recognises the vital role that the family plays in the different circumstances of admission, in complaints lodgement before the Board on behalf of the PWMD, and upon discharge of the PWMDs. For instance, parents or guardians can submit a written request for the **voluntary admission** of a PWMD who is below 16 years.[929] Secondly, in the case of **involuntary patients**, the Act permits a husband, wife, relative or any other person with just cause, to cause the involuntary admission for review and treatment of any person suffering from a mental disorder, but who is incapable or unwilling to express him or herself to receive treatment.[930] Relatives can also apply for the discharge of their PWMDs.[931]

The recognition of family role is very important since PWMDs in Kenya, just as in Uganda and South Africa, are largely dependent on their families for provision of all basic needs, including caregiving and financial support.[932] However, in some cases, this reliance on the family can create a paternalistic or protectionist system that, if not well guarded, can also result in violation of the rights of PWMDs.[933]

Therefore, although the role of the family as primary care givers is highly appreciated, there is also a need to ensure availability of CMHC and support

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[926] Where a PWMD is admitted upon his own application or that of a next of kin or parents or guardian as per section 10(1). Voluntary admission not to exceed 42 days under section (13).
[927] Section 14 on involuntary treatment is where the PWMD is incapable or unwilling at the material time to consent to admission and treatment. Involuntary admission shall not exceed six (6) months.
[928] Section 16 permits a police officer of above the rank of inspector, officer in-charge of police station, administrative officer, chief or assistant chief to take or cause to be taken into custody any person believed to be suffering from a mental disorder found within his or her jurisdiction; or who is believed to be a danger to himself or herself or who may act in a manner offensive to public decency or person suffering from mental disorder wo is not under proper care and control, or is being treated cruelly or is neglected by relatives or other person in charge of him.
[929] Section 10(2).
[930] Section 14(2).
[931] Section 22.
[932] USPK, 'Article 19 of UNCRPD', at 5.
[933] Inclusion International, 'The Global report on Article 19', at 62.

services to enable PWMDs and their caregivers, to access mental health services easily and quickly from within the community.[934]

d) Protection of the rights of PWMDs

Except for the provisions relating to protection of patients from ill treatment,[935]the management of the estate of PWMDs[936] and appointment of a guardian for such person, the MHA, 1989, unlike that of South Africa and Uganda, makes no detailed provision guaranteeing the fundamental rights and freedoms of PWMDs. Enacted prior to the adoption and ratification of the UNCRPD by Kenya, it is no wonder that the MHA, 1989 also makes no reference to the provisions of the UNCRPD. Notably, the Act was last amended in 1991 and revised in 2012, and some of its current provisions are contrary to the international standards and the Kenyan Constitution.[937] However, this anomaly is not fatal, since the Kenyan Constitution domesticates all international and regional instruments duly ratified by the country,[938] and vehemently guarantees the rights of all PWDs.[939]

As a result of the shortcomings, the MHA is currently under review and the Mental Health (Amendment) Bill, 2018 is already before Parliament for debate.[940]

5.3.2.4 A 'Birds-eye View': The Mental Health (Amendment) Bill 2018

The MH(A) Bill seeks to make provisions that conform to the Constitution of Kenya, 2010 as well as comply with Kenya's international and regional treaty obligations. It proposes a number of reforms including: resorting to use the term 'mental illness' as opposed to 'person suffering from mental disorder' or

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[934]*Ibid*, at 25-30; Verity, Turiho, Mutamba *et al*, 'Family care for PWSI', at 9.
[935] Section 51(1) states that 'Any person in charge of, or any person employed at, a mental hospital who strikes, ill-treats, abuses or willfully neglects any patient in the mental hospital shall be guilty of an offence'. but nothing in this section shall be deemed to make it an offence for the person in charge of, or any person employed at, a mental hospital to take steps he considers necessary in the interests of a patient to prevent the patient from causing physical injury to himself or to others.'
[936]Section 26-35 on management of estate of person with mental disorder and role guardian
[937]KNCHR report, 'Silenced Minds', at 20.
[938] Article 2(6).
[939] Article 54.
[940] Mental Health (Amendment) Bill 2018.

'subnormality with mental disorder';[941] inclusion of new definitions like care, treatment and rehabilitation to mean preventive and after care services, such as counselling, psychotherapy and vocational care; person suffering from mental illness; mental health facility; broadens the definition of a medical practitioner to include a psychiatrist, psychologist, clinical officer, and counsellor and a representative of mentally ill person to mean a spouse, parent, guardian, next of kin or persons;[942]spelling out in detail, the purpose of the Act.[943] The Bill also sets out a number of principles that should guide the implementations of the Act;[944] spells out the obligations of the national and county governments in a bid to decentralise service delivery and ensure easier access;[945] provides for the rights of persons with mental illness;[946] broadens the composition and functions of the Mental Health Board;[947] provides for the establishment of public and private mental health facilities;[948]prohibits the use of physical restraint and seclusion except in accordance

[941] Clause 2.
[942] Clause 2.
[943]Clause 2A which includes to promote the mental health and wellbeing of all persons, including reducing the incidences of mental illness; co-ordinate the prevention of mental illness , access to mental health care , treatment and rehabilitation services of persons with mental illness; reduce the impact of mental illness, including the effects of stigma on individuals, family and the community; promote recovery from mental illness into the communities and ensure the rights of persons with mental illness is protected and safeguarded.
[944]Clause 2B includes the promotion and fulfilment of the highest attainable standard of health as enshrined in Article 43 of the Constitution; Preservation of freedom and dignity of every human being; the fair and equitable treatment of Persons with mental illness; the protection of persons with mental illness against discrimination; accountability of duty bearers and transparency in the implementation of the Act, among others.
[945] Clause 2C and 2D.
[946] Cause 3 provides for the right to fully participate in the affairs of the community and in any position suitable and based on the person's interests and capabilities; access medicine, social and legal services for the enhancement of the protection of the rights of the person under the constitution to live in dignity and security; protection from physical and mental abuse and any form of discrimination and to be free from exploitation; to take part in activities that promote a person's social, physical, mental and emotional wellbeing; receive reasonable care and protection from their families; the right to mental health services; the right to and informed consent to treatment; the right to participate in treatment planning; the right to access medical insurance; the right to be protected from economic, social, sexual and other forms of exploitation; the right to exercise their civil, political, and economic rights as enshrined in the constitution; the right to access information; the right to confidentiality; the right to representation, and the right to recognition of their legal capacity.
[947] Clause 7-10.
[948] Clause 15.

with the law;[949] prohibits the treatment or admission without the informed consent of the person with mental illness or his/her representative;[950] reforms the procedure for voluntary admission of persons of eighteen years and above or children;[951]provides for reform of the procedure of involuntary admission of patients,[952] emergency admission and treatment,[953] and the care and administration of property of person with mental illness;[954]among others.

Laudably, the proposed reforms in the Bill attempt to address the gaps in the MHA, 1989 and ensure Kenya's compliance with the UNCRPD and the Constitution. If the Bill is passed into law, coupled with adequate staffing and financing of the mental health sector, as well as provision of accessible and effective CMHCS and support services, it will pave the way for better protection of the rights of PWMDs in Kenya and enhance the possibility of deinstitutionalisation, independent living and community inclusion.

5.3.2.5 Kenya Mental Health Policy (KMHP) 2015-2030

This policy was informed by the findings of the Kenya National Commission on Human Rights (KNCHR) that arose from an audit conducted into the state of mental health in Kenya. As elucidated earlier, the KNCHR revealed that there was a glaring gap between the legal guarantees on the right to the highest attainable standard of health as set out in Article 43 of the Kenyan Constitution and the reality in the provision of mental health services to the populace.[955] Among the various recommendations made by the KNCHR was the need to adopt a Kenyan Mental Health Policy.[956]

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[949] Clause 15 (9E).
[950] Clause 15 (9D).
[951] Clause 17 and deleting sections 11, 12, and 13 of the MHA.
[952] Clause 22.
[953] Clause 25.
[954] Clause 26-31.
[955] KNCHR report, 'Silenced Minds', at 28.
[956] *Ibid*, at 44.

The goal of the policy is targeted 'Towards Attaining the Highest Standard of Mental Health'. It is premised within the aspirations of the Kenyan Constitution 2010, the Kenya Health Policy 2014-2020, Kenya's Vision 2030 and the global commitments.[957] The Policy lays out a number of objectives which are pertinent to the promotion of mental health care. These objectives include: strengthening effective leadership and governance for mental health; ensuring access to comprehensive, integrated and high quality, promotive, preventive, curative and rehabilitative mental health care services at all levels of health care; and to implement strategies for the promotion of mental health, prevention of mental health disorder and substance use disorder and to strengthen mental health systems.

To address the shortfall in the provision of CMHCS and support services, among its priority actions, the KMHP now emphasises the need for rehabilitation of persons with Mental, Neurological and Substance use (MNS) disorders, which interventions should be at all levels. It adopts the following steps:

- Strengthening evidence-based programmes for residential rehabilitation and reintegration into the communities
- Increase availability of a range of community-based rehabilitation services
- Develop community-based programmes to support families
- Establish community recreation and therapeutic facilities with a view to socially target the persons with MNS disorders to the family and the society at large
- Development and implement programmes to facilitate persons with mental disorders to pursue education and vocational training to improve their chances of employment; establish social protection and disability benefit programmes for persons with MSN disorders.[958]

[957] *Ibid*, at 1.
[958] KNCHR report, 'Silenced Minds', at 15.

Certainly, these priority policy actions are significant in promoting the provision of CMHCS and deinstitutionalisation, as well as enhancing the realisation of the right to independent living and community inclusion. Hence, learning from both South Africa and Kenya, it is imperative that Uganda too adopts a mental health policy that emphasizes the provision of community-based mental health care and support services and promotion of empowerment, independent living, and community integration of PWMDs.

5.3.2.6 Social Assistance Act No. 24 of 2013

Like South Africa, Kenya has a Social Assistance Act (SAA) that is relevant for the support and economic empowerment of vulnerable persons including PWMDs. The purpose of the Act is to provide for the establishment of the National Social Assistance Authority (NSAA) and for the rendering of social assistance to persons in need and for connected purposes.[959] It also guarantees the provision of social services to persons in need.[960] The social services pertinent for PWDs include: rehabilitation, counselling, day care, community development and provision of income assistance.[961] PWDs are categorised as people in need and are eligible for social assistance if the person suffers from severe mental or physical disability and/ or the persons disability renders them incapable of catering for their basic needs; and there is no known source of income or support for that person.[962] The social assistance grant may lapse upon the beneficiary's death or admission to a residential institution.[963]

The Act further empowers the Minister to develop and implement social assistance programmes that are intended to: assist the development of the

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[959] *See*, the long title of the Act.

[960]Under Section 17, persons in need include: orphans and vulnerable children; poor elderly persons; unemployed persons person disabled by acute chronic illness; widows and widowers; persons with disabilities and any other person as may be determined by the Minister.

[961] Section 2.

[962] Section 23.

[963] Section 2 defines residential institution to mean an institution approved in accordance with the regulations that provide for living accommodation, and temporary or continuing care for persons in need.

individual, family and community capacity to become self-sufficient; increase the ability of persons in need to assume greater responsibility for themselves; lessen dependency by the people on public financial assistance; provide support services to allow persons who would otherwise be in need to avoid dependency on public financial assistance; and lessen, remove or prevent the causes of poverty.[964]

The enactment of the SAA and its recognition of PWDs as person in need of social assistance, services and support is highly commendable. However, it presents a number of shortcomings including the promotion and support to residential institutionalisation contrary to Article 19 of the UNCRPD and 14 of the ADP.[965] It is also reported that the SAA has never been operationalised, and yet the government recently introduced the Social Assistance (Repeal) Bill 2020 which seeks to repeal the SAA and enable the operationalisation of the Social Assistance Fund.[966]

Indeed, the legislative terrain in Kenya provides a fertile ground for the protection and promotion of the rights of PWDs in Kenya. It can also be purposively utilised to promote provision of CMHCS and the right to independent living and community integration and inclusion for PWMD. However, as earlier noted, positive or progressive legislation alone is not the sole solution. The government must take measures to effectively implement the provisions enshrined in the various laws,[967] as well as address the glaring gaps evident in the mental health sector like inadequate funding and staffing, lack of alternatives like CMHCS, providing support to the family as primary caregivers, and ensuring the effective operation of the mental health board.

The next section examines the existing programmatic interventions adopted by Kenya to promote independent living and community inclusion for PWMDs.

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[964] Section 24.
[965] Section 2(c).
[966] The African Platform for Social Protection, 'Repeal of the Kenyan Social Assistance Act 2013'.
[967] Agwel, 'Kenya in Implementing the UNCRPD', at 8.

5.4 Progress towards Realising the right to Independent Living for PWMDs in Kenya

Although institutionalisation of PWMDs is a dominant practice in Kenya,[968] some PWMDs in the country live with their families and are highly dependent on them. Others are abandoned, neglected and homeless.[969] Hence causing high levels of vulnerability and at risk of abuse. This is attributed to the lack of the desired skills and community-based alternatives that hinder their ability to live independently and be included in their communities.[970] PWMDs who depend on their families may also be subjected to paternalistic approach and protectionism that hinders the enjoyment of their legal capacity and independent living.[971] USPK observed that,

> Family based support for people with psychosocial disabilities is usually supply driven; provided on the carer's terms rather than based on the will and preference of the individual. In part this is because Kenya does not provide incentives or any manner of compensation to families for their role as carers. Overreliance on family based support creates a context of dependency that makes it difficult for people with psychosocial disabilities to exercise choice and control not only with regard to issues arising under article 19, but also with regard to exercising the right to legal capacity as provided for under article 12 of the CRPD.[972]

Hence the need for government interventions to the realisation of the right to support legal capacity as well as independent living and inclusion. Kenya has a number of legal and programmatic initiatives to support PWDs which include: the Cash Transfer Programme under the National Development Fund for Persons with Disabilities (NDFPWDs); the Economic Empowerment Project 2010; the Cash-Transfer Programmes for Persons with Severe Disabilities; and the tax exemption for PWDs.[973] This section examines the extent to which these practical measures

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[968] USPK, 'Article 19 of the UNCRPD', at 2.
[969] *Ibid*, at 5.
[970] Runo, 'Independent Living', at 1-2.
[971] USPK, 'Article 19 of the UNCRPD', at 5; Inclusion International, 'A Global Report on Article 19', at 57-60.
[972] *Ibid,* at 5.
[973] Kenya National Report to the CRPD Committee, at 33.

promote the right to independent living and community inclusion for PWMDs in Kenya.

5.4.1 The Cash Transfer Programme under the NDFPWDs

The National Development Fund for Persons with disabilities (NDFPWDs) is established under section 32 of the Kenya's PWD Act. According to the Act, the funds held in trust by the Board of Trustees is used inter alia: to contribute to the capital expenses of organisations of or for PWDs; to contribute to the expenses of institutions that train persons in the care of with disabilities; to contribute towards government projects to benefit PWDs; to provide or contribute to the cost of assistive devises and services; to pay allowances to persons with severe disabilities who often have no other source of income and are not trainable in any skills, aged persons with disabilities and single parents with children with disabilities who cannot therefore seek employment.[974] KNCHR reported that NDFPWDs empowers PWDs to be independent by providing and contributing to the cost of assistive devices and services.[975]

Over the years, the Kenyan government has increasingly set aside some funds for the NDFPWDs. For instance, the government allocated KES 200 million, KES 200 million and KES 250 million in FY2009/2010, 2010/11 and 2011/12 respectively.[976]

However, Kamudia argues that NDFPWDs is grounded in the Kenyan PWD Act, which unfortunately lacks an enforcement mechanism and that this severely hampers its impact on the ground in benefiting PWMDs.[977] Indeed, I was unable to find any information regarding access of these funds by PWMDs.

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[974] Section 32(2).
[975] Kenya National Commission for Human Rights (KNCHR) Report: Compendium on Submissions to the CRPD 2016, at 28-29; Kenya National Report to CRPD Committee, at 33-34.
[976] *Ibid*, at 37.
[977] Kamundia, 'Charting the Way Forward', at 20.

5.4.2 Persons with severe disabilities Cash Transfer Programme

This is established under the Ministry of Gender, Children and Social Development in collaboration with the National Council for Persons with Disabilities (NCPWDs). The programme targets all severe disability categories such as cerebral palsy, autism, deaf-blindness, spinal bifida, quadriplegia, mental disability, spinal injury, paraplegia, down syndrome, muscular dystrophy, other multiple disabilities, among others. The rationale of the programme is premised on the fact that severe cases of children and adults with disability need full time support to ensure that their needs are addressed. This may deny their caregivers the opportunity to engage in meaningful income-generating activities and therefore increase their vulnerability and that of other members to extreme poverty.[978] Under the programme, a person with severe disability has been defined as 'an individual who depends on a care taker for feeding, toiletry, sanitary and other needs, and who requires round the clock care thus denying a member of the household an opportunity to earn a livelihood'.[979] At the pilot stage, 10 persons were targeted from each of the 210 constituencies in Kenya, totalling to 2,100 persons with severe disabilities, with each receiving a monthly cash transfer of KES 1,500. In Financial Year 2011/2012, the government increased the amount from KES 25 million to KES 385 million and the number of beneficiaries to 14,700. The transfer amount increased to KES 2,000 per person per month.[980] In Financial Year 2015/16, the programme had covered 45,505 households.[981]

However, despite the laudable purpose of the Cash Transfer Programme in Kenya, the National Gender and Equity Commission (NGEC) report identified a number of challenges that hinder effective access by the beneficiaries. These

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[978] National Gender and Equity Commission Report (NGEC), 'Participation of Vulnerable', at 12.
[979] KNCHR Report, 'Compendium on Submissions to the CRPD', at 37.
[980] *Ibid*, at 37.
[981] The National Safety Net Program. Available at https://www.socialprotection.or.ke/social-protection-components/social-assistance/national-safety-net-program/cash-transfer-for-persons-with-severe-disabilities-pwsd-ct; See also, National Gender and Equity Commission Report (NGEC), at 12.

included: lack of adequate and correct information on the process of enrolling onto the programme; lack of beneficiary identification cards; delay in transfer of funds leading to inconveniences in planning for the household and increased vulnerability; indirect costs of transportation, among others.[982] Users and Survivors of Psychiatry-Kenya (USPK) have also noted that PWMDs hardly access these funds.[983]

5.4.3 Training and rehabilitation services

In order to live independently in the community, PWDs require empowerment and training in various areas such as the ability to make choices and participate in all aspects of life in the service they require.[984] Kenya has established education facilities and rehabilitation centres that offer life skills and vocational training to PWDs to enable them use assistive devices and live independently.[985] There are 12 vocational rehabilitation centres across the country which offer training in different fields that seek to empower PWDs to enable them enter into formal, informal and/ or self-employment.[986] The centres are: the Industrial Rehabilitation Center in Nairobi; Bura Rehabilitation Centre; Embu Rehabilitation Centre; Muriranjas Rehabilitation Centre; Nyandarua Rehabilitation Centre; Kabarnet Rehabilitation Centre; Kericho Rehabilitation Centre; Kisii Rehabilitation Centre; Itando Rehabilitation Centre; Kakamega Rehabilitation Centre; Odiado Rehabilitation Centre; and Machakos Vocational Rehabilitation Centre. The current student enrolment in the Vocational Centers stands at 500. In order to achieve integration, the Centres have adopted the integration policy where 60% of the students are PWDs and 40% non-disabled.[987] Unfortunately, I found no information confirming the number of PWMDs enrolled in or who have benefited from these centres, or whether the nature of training offered is beneficial to them.

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[982] NGEC Report, at 29.
[983] USPK, 'Article 19 of the UNCRPD,' at 4.
[984] Runo, 'Independent Living', at 12.
[985] KNCHR Report, 'Compendium on Submissions to the CRPD', at 28.
[986] *Ibid*, at 34.
[987] *Ibid*, at 36.

5.4.4 Partnerships with NGOs

In addition to these, the government is working closely with the Development Partners and NGOs like the Association of Persons with disabilities in Kenya (APDK) to promote independent living through provision of education, vocational training and CBR programmes.[988] These efforts are geared towards economic empowerment of PWDs, life skills development and self-reliance. A number of other NGOs are complementing government in providing community-based services and social support to PWMDs, supporting families with PWMDs, supporting self-advocacy and mental health service user groups in advocacy, and engaging PWMDs and their families in poverty alleviation programmes.[989]

Unfortunately, these efforts by the Kenyan government are inadequate in addressing the right to independent living and community inclusion in the society for PWMDs. Notably, the current measures have no mention of the concept of independent living.

Premised upon the above discussion, it is evident that Kenya, like Uganda and South Africa, can boast of progressive laws that seek to protect and promote the rights of PWMDs. However, practical efforts towards combating stigma and discrimination against PWMDs, adequate provision of CMHCS and support services and realising the right to independent living and community inclusion for PWMDs, are still inadequate. The few initiatives in place are deficient in benefiting PWMDs, and there is no data confirming PWMDs' ability to access and benefit from the current programmes. In addition, physical, environmental, information and communication barriers prevent PWDs from living independently and participating fully and on an equal basis with others in society.[990] Hence, the Kenyan government

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[988] Kenya National Report to the CRPD Committee, at 34.
[989] *Ibid*, at 28.
[990] 'Report for the Coalition of Disability Sector NGOs for Universal Periodic Review (UPR) – Kenya (2015)', at 1.

seriously needs to address these challenges to deepen the benefits of these Cash Transfer Programmes.

Nevertheless, the Uganda government can 'borrow a leaf' from the strategies instituted by their Kenyan counterparts to address the challenges facing PWMDs. For instance, it could put in place a funding stream similar to the Persons with Severe Disabilities Cash Transfer model and the Persons with Severe Disabilities Cash Transfer Funds Programme to specifically support PWMDs and their caregivers and to address poverty and other vulnerabilities attributable to the burdens of caregiving. Furthermore, the government should ensure that both PWMDs and caregivers have access to the already existing economic empowerment programmes like the Youth Livelihood Programme, Uganda Women Entrepreneurship Programme, the Parish Development Model, *Emyooga* and the disability grants too. It should also deepen collaboration with Disabled Peoples' Organisations (DPOs) focusing on mental health care to identify and implement CMHC and support services. In so doing, Uganda will be moving towards addressing part of the recommendations made by the UNCRPD Committee to her.[991]

[991] UNCRPD Committee, Concluding Observations CRPD/C/KEN/CO/1: para 15-16 where the Committee recommended that Kenya embarks on long-term strategy aimed at raising awareness and combating discrimination against persons with disabilities.

The table below presents a brief summary of the preceding discussion.

DESCRIPTION OF ELEMENTS OF COMPARISON	UGANDA	SOUTH AFRICA	KENYA
Dated of Ratification of / Acceding to the UNCRPD	25th September, 2008	30th November 2007	19th May 2008.
Date of Ratification of / Acceding to ADP	Not yet ratified	Not yet Ratified	Not yet ratified
Provision of CMHCS	Not available	Not available	Not available
National Legal framework and provisions that relate to rights of PWDs and relevant to the promotion of the right to independent living and community inclusions	-Uganda Constitution, 1995 (As Amended) Articles: 20,21,32, 35 -Persons with Disabilities Act, 2020: Sections -Mental Health Act, 2019: Sections 3, 4, 20,21, 24, 29,30,42,51-58, 63 -Children Act, Cap 59 (As Amended by the Children Amendment Act, 2016) Sections 3, 4, 9	-South African Constitution, 1996: Sections 9, 10,11,12,13,26,27 and 29 - Promotion of Equality and Prevention of Unfair Discrimination (PEPUDA/the Equality Act): Section 9on non-discrimination	-Constitution of Kenya, 2010: Articles: 19, 20, 26, 27, 28, 54 - Persons with Disabilities Act No.14 of 2003: Sections 12-24, 45 - Person with Disabilities (Cost, Care, Support and Maintenance) Regulations 2009

	-National Disability Policy 2006 -National Development Plan 111 (2020/21-2024/25) -	-Mental Health Care Act, 2002: Sections 3, 4, 5,7,8,9,11, 19 -- The National Mental Health Policy Framework and Strategic Plan 2013-2020 - Government White Paper on the Rights of Persons with Disabilities, 2015 - Social Assistance Act (SAA)No. 13 of 2004. Sections: 3, 4, 5, 12, 24-27	- Mental Health Act (Cap 248), 1989: Sections 5,10,14,16, 51, -Kenya Mental Health Policy 2015-2030. - Social Assistance Act No. 24 of 2013: Section 2, 23, 24
Support Initiatives for PWDs	-Community-based Rehabilitation programmes following the WHO-CBR Guidelines under MGLSD not reaching PWMDs -Special Grants for PWDs to enhance	-Provision of 149 residential facilities for PWMDs to avoid institutionalisation -Very limited provision of Community based Rehabilitation and CMHCS	- The Cash Transfer Programme Programme through the National Development Fund for Persons with Disabilities established under section 32 of the PWD Act. Not accessed by PWMDs

	economic empowerment -Youth Livelihood Programme (YLP) -Uganda Women Entrepreneurship Programme (UWEP) -Parish Development Model	-Provision of Disability Grant under the SAA -Special Covid 19 relief distress grant - Child Support grant -Disability grant -Grant-in Aid	- Persons with severe disabilities Cash Transfer Programme under Ministry of Gender, Children and Social Development - Training and rehabilitation services various Industrial Rehabilitation Centres - Partnerships with NGOs to provide community-based support services
Supported Employment Initiative	Not available	-Sheltered Workshops -Integrated Enterprises and supported employment -Open labour market	Not available

		-260 Protective workshops -Tax exemption	

5.5 Conclusion

The above analysis reveals that there are several similarities between South Africa, Kenya and Uganda in the context of promotion and protection of the rights of PWMDs. These include: the continued state of marginalisation, discrimination and stigmatisation of PWMDs in the communities; the generally poor state of mental health care, coupled with limited human resource and budgetary allocation to the sector; the prevailing medical model of managing PWMDs that still influences the laws and practices in the management of PWMDs; the persistent practice of long-term institutionalisation of PWMDs in mental health facilities, though the precise number of PWMDs institutionalised may difficult to establish due to data limitations; the general inadequacy of statistical data regarding PWMDs. Other areas of similarities include: the presence of progressive legal and policy frameworks for the protection and promotion of the rights of PWMDs; the establishment of a mental health review board to perform both administrative and quasi-judicial functions in monitoring provision of mental health care and services in mental facilities; the limited efforts towards the promotion and provision of CMHCS and support services; the need to develop a comprehensive strategy for deinstitutionalisation and programmes that promote the realisation of the right to independent living and community inclusion for PWMDs. It is clear that most of the existing support services have primarily benefited persons with other forms of disabilities leaving PWMDs lagging behind and thus exacerbating their already high levels of exclusion and vulnerability.

Despite the shortcomings in South Africa and Kenya, a number of measures are being implemented in the two countries from which Uganda can draw lessons and

improve her efforts geared towards supporting PWMDs to live independently and be included in their communities.

The following chapter discusses the strategies that Uganda can adopt to promote independent living and community inclusion for PWMDs in line with Uganda's obligations in Articles 19 of the UNCRPD and 14 of the ADP (upon ratification).

CHAPTER SIX

BEST PRACTICES TOWARDS ACHIEVING INDEPENDENT LIVING AND COMMUNITY INCLUSION FOR PWMDs IN UGANDA

> *The exclusion, marginalization and stigma faced by PWMDs in the larger community context...requires a fundamental shift within the mental health field, in order to end the current situation. This means rethinking policies, laws, systems and services and practices across the different sector which negatively affect people with mental health conditions and psychosocial disabilities, ensuring that human rights underpin all actions in the field of mental health...This means a move towards a more balanced, person-centred, holistic and recovery-oriented practices that consider people in the context of their whole lives, respecting their will and preferences in treatment, implementing alternatives to coercion, and promoting right to participation and community inclusion.* [992]

6.0 INTRODUCTION

As discussed in Chapter Four, Uganda has passed some progressive legislation and taken some measures to protect the fundamental human rights of all PWDs and improve their standard of living. However, gaps still exist and the unique needs of PWMDs have largely remained unaddressed. For instance, although the new MHA, 2019 recognises the need for CMHCS, the general lack of financial resources, limited staffing of the health personnel and drug stockout hinder the provision of the services by the various mental health facilities.[993] Yet, the provision of CMHCS is undoubtedly key in enhancing access to mental health care services, decongesting the mental health facilities, combating institutionalisation and promoting the realisation of the right to independent living and community inclusion, as well as enabling PWMDs to live a better quality of life.[994] Hunt and Mesquita rightly observe that increased knowledge about mental disabilities and new models of

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[992] WHO, 'Guidance on Community Mental Health Care', at 3; WHO, Mental Health Action Plan (2013-2020) now extended to 2030, at 7 also reiterates that, in light of widespread human rights violations and discrimination experienced by people with mental disorders, a human rights perspective is essential in responding to the global burden of mental disorders.

[993] Twinomugisha, 'A Health and Human Rights Critique', at 14-15; Ojok, 'Mapping and Assessment', at 27-28.

[994]WHO, 'Pyramid Framework', at 2; WHO, 'Guidance on Community Mental Health Care', at 8-10; ISER, 'Analysis of the Mental Health Bill 2014', at 5-6; Kabale, 'Submission to the Health committee', at 4.

community-based services and support systems have allowed many people with mental disabilities (once relegated to living in closed institutions) to demonstrate that they can live full and active lives in the community. People once perceived to be incapable of making decisions for themselves have shattered stereotypes by showing that they are capable of living independently when appropriate legal protections and support services are provided.[995]

However, because of the inadequacies in the provision of CMHCS, the dominant practice of institutionalisation of PWMDs and provision of medications alone prevails as the main mode of treatment and care to PWMDs. The UNCRPD Committee has recommended that Uganda should,

> (a) Adopt a strategy for the de-institutionalization of persons with disabilities, within a timeframe and indicators;
>
> (b) Provide essential community-based services, including accessibility to education, health and employment and accommodation, personal assistance to guarantee independent living for persons with disabilities, including those living in rural areas;
>
> (c) Provide grants to persons with disabilities to facilitate independent living in the community covering support for assistive devices, guides, sign language interpreters and affordable skincare protection for persons with albinism.[996]

Commendably, in response to the UNCRPD Committee recommendations, Uganda has adopted the National Comprehensive Action Plan on the Rights of Persons with Disabilities 2020-2024 (NCAPPWDs), wherein, it commits to:

a) Adopt a Community Based Rehabilitation Strategy for deinstitutionalisation, disseminate and implement it within a timeframe.
b) Provide essential community-based services, including accessibility to education, health, employment, accommodation, personal assistance to

[995] Hunt and Mesquita, 'Mental Disabilities', at 334.
[996] UNCRPD Committee, Concluding Observations, para. 40.

guarantee independent living for PWDs, including those living in the rural areas.

c) Provide grants to PWDs to facilitate independent living in the community covering support for assistive devices, guides, sign language interpreters and affordable skincare protection for persons with Albinism.[997]

Premised upon the foregoing, this chapter explores the different strategies that could be adopted by Uganda to ensure that PWMDs realise their right to independent living and community inclusion on an equal basis with their non-disabled counterparts. The proposed strategies are timely and largely informed by the lessons learnt from the South African and Kenyan context, as well as other literature. Notably, most of the strategies proposed herein have recently been adopted by the UNCRPD Committee in its Guidelines on Deinstitutionalisation.[998]

6.1 PRACTICAL STRATEGIES

6.1.1 Develop and Implement a deinstitutionalisation plan

Government must develop a deinstitutionalisation plan in order to promote community health care and independent living for PWMDs. The UNCRPD Committee recommends that Deinstitutionalization plans should ensure that all persons with disabilities have access to a variety of accessible, affordable and high-quality mainstream services in areas such as personal mobility, accessibility, communication, health care, family life, an adequate standard of living, inclusive

[997] MGLSD, 'The National Comprehensive Action Plan on Persons with Disabilities (NCAPWDS) 2020-2024', at 15. Adopted in August 2020 (copy on file with Author).

[998] Para 99-106 providing for the various actions States must take to realise the right to independent living for all PWDs leaving institutions including: provision of wide range of services needed for daily living on an equal basis with others; support awareness-raising activities; ensure access to transport for persons living institutions; ensure accessibility of public spaces; provision of comprehensive health care; access to employment; provision of social protection package to combat the risk of poverty; ensure access of PWDs and their families to social protection measures such as child support, unemployment benefit, rental subsidies, food stamps, pensions, public health schemes, subsidized public transport and tax credit; access to inclusive education without discrimination.

education, participation in political and public life, housing, social protection, and participation in cultural and community life, leisure, recreation and sport.[999] Deinstitutionalisation of mental health facilities and promoting community-based mental health care is the contemporary agenda.[1000] In spite of this, the WHO observes that mental hospital-based care in long-stay institutions still remains the dominate mode of service delivery to PWMDs in many countries, including Uganda.[1001] Salisbury, Killaspy and King's assessment of European countries confirms the slow process towards deinstitutionalisation.[1002]And yet, institutionalisation of PWMDs in mental facilities or prisons hampers their ability to exercise and enjoy the right to independent living and community integration and inclusion of PWMDs in their societies.[1003]

Uganda should adopt a deinstitutionalisation plan for PWMDs institutionalised in mental facilities.[1004] However, the deinstitutionalisation process must be preceded by the provision of alternative affordable, accessible, adaptable and quality CMHCS and support services developed in consultation with mental health users, their families and other DPOs.[1005] The WHO survey identified five principles for an effective deinstitutionalisation process, namely:

- Firstly, community-based services must be in place so that deinstitutionalization does not result in homelessness, incarceration, or neglect of former residents; nor does it leave families to fend for themselves.
- Second, health workers and health professional bodies should be actively involved in the planning, implementation, and monitoring of reform;

[999] UNCRPD Guidelines on Deinstitutionalisation, 'para 90.
[1000] WHO, 'Mental Health Action Plan', at 10. Objective (2) para 22 of the Mental Health Action plan is to provide comprehensive, integrated and responsive mental health and social care services in community-based settings.
[1001]WHO Report, 'Innovations in Deinstitutionalization', at 12.
[1002] Salisbury, Killaspy and King, 'Deinstitutionalisation of mental health care', at 7.
[1003] ISER, 'Analysis of the Mental Health Bill 2014', at 5-6.
[1004] Verity, Tuhiro, Mutamba *et al*, 'Family care for PWSI', at 2-3.
[1005] ENIL, 'Barriers to the Right to Independent Living', at 29-30; Inclusion International, 'Global Report on Article 19,' at 65-67; Ojok, 'Mapping and Assessment', at 39.

- Third, a range of government sectors, academic leaders, non-governmental organizations, and service users and their families have important roles to play to help strengthen the transformation of mental health service delivery.
- Fourth, contextual transformations such as emergency situations and changes in political leadership should be considered for their ability to create openings for deinstitutionalization.
- Finally, additional financing is needed to support the transition from institutional care to community-based care.[1006]

Hence, government must embark on a proper process of deinstitutionalisation in a manner that upholds human rights and promotes integration and inclusion of PWMDs in their communities. Re-institutionalisation or even segregation in smaller group homes/houses, family-type centres, protected houses, living centres, day care facilities, church shelters, community villages and the like, if not well monitored, will still result in institutionalisation.[1007]

It is therefore imperative that the process of deinstitutionalisation supports PWMDs to live in their own homes, or within their community, if they so wish, with the necessary support and assistance to enable independent living and community inclusion.[1008] In other cases, PWMDs can be supported to live with their families as their primary care givers.[1009] In addition, cash transfer programmes and provision of disability grants or in-kind grants can be extended to the individual or family to support them access basic needs and lessen the burden of caring for the PWMDs as is the case in Kenya and South Africa.

[1006] WHO, 'Report: Innovations in Deinstitutionalization Process', at 40; ENIL, 'Barriers to the Right to Independent Living', at 30; WHO, 'Pyramid Framework', at 2; UNCRPD Guidelines on Deinstitutionalisation: para 93-98 detailing the steps to be taken in preparation for deinstituionalisation.
[1007] ENIL, 'Barriers to the Right to Independent Living', at 25.
[1008] WHO, Guidance to Community Mental Health Services', at 9-10; Inclusion International, 'Global Report on Article 19', at 67-68; Kabale, 'Submission to the Parliament Health committee', at 4.
[1009] Verity, Tuhiro, Mutamba *et al*, 'Family care for PWSI', at 7-8; Inclusion International, 'Global report on Article 19', at 25-27.

6.1.2 Ensure the provision of community-based mental health care services (CMHCS)

Provision of CMHCS integrated within the PHC system is another step towards realising the right to independent living and community inclusion for PWMDs. The WHO Atlas reveals very low levels of provision of functional integration of mental health care into primary health care in Africa.[1010] The WHO has called on States to adopt the WHO Pyramid Framework of provision of community-based health care in order to broaden access to health care at community level and reduce costs of institutionalised care.[1011]

Despite this, access to both health care and mental health care services remains a challenge for many PWMDs globally.[1012] This is due to several factors including the limited availability, accessibility and affordability of the full range of quality health care services.[1013] Yet, promoting the right to health as enshrined in Articles 25 of the UNCRPD and 17 of the ADP is fundamental to living an adequate standard of life as protected in the laws.[1014]

Provision of adequate, accessible and affordable CMHCS is critical in enhancing access to mental health care and in the pursuit for deinstitutionalisation and promotion of independent living and community inclusion.[1015] Booyens, Pletzen and Lorenzo contend that the purpose of CMHCS services is to shift away from institutionalisation and also empower PWDs to advocate for themselves, as far as they are able to, and to participate in full community life.[1016] Similarly, both Twinomugisha, and Simpson and Chipps opine that a strong system of primary health care services and community-based services is also required to support

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[1010] WHO, 'Mental Health Atlas 2020', at 76-77.
[1011] WHO, 'Pyramid Framework', at 1-6.
[1012] WHO, *World Health Report*, at 3; WHO, 'Guidance on Community Mental Health Services', at 3.
[1013]United Nations Department of Economic and Social Affairs, *Disability and Development Report*, at 47.
[1014] Article 28 of the UNCRPD and Article 20 of ADP guarantee the right to an adequate standard of life for PWDs.
[1015]Cappo, Mutamba and Verity, 'Belonging Home', at 5; WHO, *World Health Report*, at 50; ISER, 'Analysis of the Mental Health Bill 2014', at 6.
[1016] Booyens, Pletzen and Lorenzo, 'The Complexity of rural contexts', at 9.

deinstitutionalisation and the integration of previously institutionalised mental health care users with severe and chronic psychiatric problems into the primary health care system.[1017] Once mental health services are closer to the users, this will inevitably reduce the number of PWMDs seeking admission or services in general hospitals or regional mental health facilities. Institutionalisation will be retained primarily for the critical cases that need institutionalised care.[1018] In advocating for CMHCS, Kabale Benon opines that,

> One thing I know is that recovery is in the community, not the hospital, so bringing services nearer to the community ensures community care towards the victims, thus a quick recovery, it brings the victim closer to their family, and reduces the number of people in the hospitals.[1019]

In addition, provision of CMHCS at PHC centres also reduces expenditure on transport costs and the time both the PWMDs and their caregivers spend travelling to the health facility and back to their homes. This in effect allows them to not only reduce these incidental expenses, but also to engage in other activities that may improve their economic status and that of their households, and also lessen the burdens of care-giving.[1020] Hunt and Mesquita advocate that

> States should take steps to ensure full package of community based physical and mental health care and support services conducive to health, dignity and non-discrimination. The ideal package should include medication, psychotherapy, ambulatory services, hospital care for acute admissions, residential facilities, rehabilitation of persons with psychiatric disabilities, programmes to maximise the independence and skills of persons with mental illness like, supported housing and employment, income support, inclusive and appropriate

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[1017] Simpson and Chipps, 'Mental Health Legislations', at 53; Twinomugisha, 'A Health and Human Rights Critique,' at 17.
[1018] Ojok, 'Mapping and Assessing', at 24; ISER, 'Analysis of the Mental Health Bill 2014', at 5-6; WHO, 'Pyramid Framework', at 2.
[1019] Ojok, *ibid*, at 25. As stated during an interview conducted with him on the 27th January 2021 for the study; Kabale Benon, 'Submission to the Parliament committee on Health', at 4; Kabale, 'Personal Experience,' at 1; ISER, 'Analysis of the Mental Health Bill, 2014', at 5-6; NUDIPU, 'Consultative meeting on the Mental Health Bill', at 4.
[1020] Ojok *ibid*, at 24; ISER, 'Analysis of the mental Health Bill 2014', at 6.

> education for children with mental illness, and respite care for families looking after a PWMDs twenty-four hours a day.[1021]

MDAC and MHU earlier revealed that provision of CMHCS is hindered by: limited staff training on provision of alternative care; super-specialised services at Butabika; abandonment of PWMDs at mental health units by their relatives; limited funding to explore alternative models of care; unaffordable and inaccessible medication in the community; and over reliance on aid agencies to run community outreach programmes.[1022] Commendably, the MHA, 2019 (as noted earlier) already recognises the need for CMHCS and provision of mental health care services at primary health centres.[1023] Unfortunately, it does not spell out the government's role and strategy in ensuring that the provision of CMHCS are actualised. Parliament's Sectoral Committee on Health urged the government to establish a framework for extending mental health care services to regional and primary health care centres, and also encourage the private sector to participate in mental health care.[1024]

It is recommended that the government adopts and effectively implements the National Community-based Mental Health Care Guidelines outlining the CMHCS Model for Uganda.[1025] Similarly, Twinomugisha calls on government to develop a Mental Health Policy and Strategic Plan to aid in the implementation of the MHA, 2019, and also to develop relevant regulations to give effect to the critical provisions of the Act.[1026] In the same breadth, Ssebunya, Kigozi and Ndyanabangi, in advocating for the adoption of a mental health policy, argued that mental health policies and plans are essential tools for coordinating all mental health services and essential in improving provision of mental health care in Uganda.[1027] This should be

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[1021] Hunt and Mesquita, 'Mental Disabilities', at 345.
[1022] MDAC and MHU, 'Psychiatric hospitals', at 44.
[1023] Section 3(a) and 20(1-4).
[1024] Parliament of Uganda, *Report of the sectoral committee on Health on the Mental Health Bill, 2014*, at 10.
[1025] *Ibid*, at 14.
[1026] Twinomugisha, 'A Health and Human Rights Critique', at 46. Currently, the Ministry of Health-Mental Health Desk has developed the Draft Mental Health Policy 2011, which unfortunately does not include the reforms adopted in the MHA, 2019, the UNCRPD and strategies to providing community-based mental health care and support services.
[1027] Ssebunya, Kigozi and Ndyanabangi, 'Mental Health Policy', at 1.

in addition to ensuring adequate financing and human resourcing of the mental health facilities at all levels to implement the adopted model and effectively provide CMHCS.[1028] Based on the empirical findings, Ojok opines that:

> Considering participants' overwhelming preference for, and appreciation of the benefits of community based mental health services, it is imperative that the government enhances the financial and human resource capacity of regional referral hospitals and lower health facilities to provide effective mental health care services at all levels. It appears that many mental health service users and caregivers would prefer to receive mental health care and treatment from the community provided they can get quality care.[1029]

This is in addition to better coordination with other service providers at community level such as: the Local Council leaders, DPOs, Village Health Teams (VHTs), traditional healers and Faith based healers to act as mobilisers and referral agents of PWMDs for mental health care intervention.[1030] The provision of CMHCS will in effect support community inclusion, participation, combat stigmatisation and discrimination of the PWMD in the community, as well as enhance access to mental health services in compliance with sections 7 and 8 of the PWD Act, 2020[1031]and reduce institutionalisation.[1032]

6.1.3 Providing Community -based Support Services (CBS)

The Uganda government needs to provide CBS services to PWMDs in order to promote independent living and community inclusion. The WHO reveals that on the African continent, a limited number of PWMDs receive social support services.[1033] Both Articles 19 of the UNCRPD and 14 of the ADP enjoin States Parties

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[1028] Ojok, 'Mapping and Assessment', at 27-28; Twinomugisha, 'A Health and Human Rights Critique', at 17.
[1029] *Ibid,* at 25-26.
[1030] *Ibid,* at 26.
[1031] Section 7 prohibits discrimination in the provision of health care services. Section 8 further enjoins the government to provide habilitation and rehabilitation services and programmes, including counseling services, and also inform the PWDs and their parents, guardian, caregivers or members of the communities where PWDs are resident of the habilitation and rehabilitation services available.
[1032] Simpson and Chipps, 'Mental Health Legislation', at 51.
[1033] WHO, 'Mental Health Atlas 2020', at 102.

to ensure provision of CBS services to all PWDs to promote their inclusion and participation in society.[1034] One of the main reasons for institutionalisation is the lack of CBS in the community, which results into discrimination and social exclusion of PWMDs.[1035] The WHO defines ccommunity-based support services to mean measures adopted to provide support and services for PWDs to live and participate in the community.[1036] Yet, CBS is a vital component in addressing social exclusion, inaccessibility of services and ensuring improved health and productivity for all vulnerable persons including PWMDs.[1037] This also enables a transition from institutionalisation to provision of CMHCS, and promotes the realisation of the right to independent and community living.[1038] ENIL states that CBS services

> Comprise a wide range of measure that must be accessible, available, affordable and acceptable by PWDs and necessary to support their community livings and inclusion in society. These measures can include: personal assistants, communication assistance (like sign language interpreters, alternative and augmentative communication), technical aids and assistive technologies, support persons, peer support, self-advocates, psychosocial support and counselling, vocational skills training, community home visits and adaptable housing among others.[1039]

Furthermore, the CBS services must also be designed in consultation with and to suit the needs of the individual with disability.[1040] As ENIL states,

> Disabled people should have choice and control over their support and should be able to make decisions about the type of support they want and who, where and when and how it will be provided, based on their preferences…Adequate and accessible information and support should

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[1034] UNCRPD Guidelines on Deinstitutionalisation, para 22-28 on the provision of community based support; para 69-82 on provision of support systems and services. These include personal assistance, peer support, supportive caregivers for children in family settings, crisis support, support for communication, support for mobility, assistive technology, support in securing housing; household help and others.
[1035] EEG, 'Common European Guidelines on Transition', at 26.
[1036] WHO, 'Assistance and Support'.
[1037] WHO, 'WHO-CBR Guidelines', at 2.
[1038] Runo, 'Independent Living', at 11.
[1039]ENIL, 'Barriers to the Rights to Independent Living', at 31.
[1040]UNCRPD Committee, General Comment No. 5: para. 30; Mugisha, Ssebunya, Hanlon *et al*, 'The experience of mental health service users', at 2.

> be provided to disabled people and their families to allow for real choice…Disabled people and their organisations should be involved in the planning and development of support services.[1041]

Inclusion International notes that, for most people who have intellectual disabilities the only support they receive in their day-to-day lives is from their families. This means that living at home with their families is the only place they can get the support that they need. Many governments, including those that have ratified the UNCRPD, have failed to provide individualised flexible supports and services.[1042]

So, for Uganda to meet its obligations, it is vital to ensure that CBS services are provided equitably in both the rural and urban communities so as to enable better community inclusion for PWMDs.[1043] Like Uganda, both South Africa and Kenya are equally lagging behind in the provision of CMHC and CBS services to PWMDs.[1044] This thesis argues that all the three countries ought to develop CMHC and CBS services in consultation with mental health care users, their caregivers and DPOs.

6.1.4. Ensure access to social amenities

Government must ensure that PWMDs have access to social amenities in order to enjoy the right to independent living and community inclusion. These social amenities include transportation, health, education, water and other social services. Accessibility of social amenities remains a major challenge for PWDs in Uganda.[1045] Yet, accessibility as a right is recognised in Articles 9 of the UNCRPD and 15 of the ADP. Accessibility is defined to mean the provision of flexible facilities and environment, either virtual or physical, to accommodate each user's needs and

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[1041] ENIL, 'Barriers to the Right to Independent Living', at 37.
[1042] Inclusion International, 'Global report on Article 19', at 64.
[1043] Ojok, 'Mapping and Assessment', at 25-26.
[1044] Simpson and Chipps, 'Mental Health Legislations', at 51-54.
[1045] NUDIPU, 'Disability Demands', at 20-22.

preferences.[1046] The UNCRPD Committee as well as Shakespeare have both emphasized the fact that PWDs lack available, acceptable, affordable, accessible and adaptable services and facilities, such as transport, health care, schools, public spaces, housing, theatres, cinemas, goods and services, and public buildings.[1047] ENIL also argues that the insufficient attention paid to making community services and facilities accessible hinders disabled people's full inclusion and participation in society.[1048]

In view of the above, the Uganda government's renewed commitment to disability inclusion as expressed in its policy documents is not misplaced.[1049] Government is therefore obligated to ensure the disability mainstreaming of public services to enable access by PWMDs on an equal basis with others and in compliance with Article 19(c). This provision calls on States to ensure that community services and facilities for the general population are available on an equal basis to PWDs, are inclusive and responsive to their needs.[1050]

Suffice to note that Uganda, like South Africa and Kenya, have in their respective legislation and policies demonstrated the political commitment to transform the dire situation for PWMDs. For instance, Article 35 of the Uganda Constitution, 1995 enjoins the State and non-State actors to promote disability rights and ensure that PWDs are productive and exhaust their full potential. To operationalise this provision, the PWD Act, 2020 enjoins both government and non-government actors to ensure access to and provision of education services, health, employment, buildings and transportation and commercial services to PWDs without discrimination.[1051] As Fox rightly observes, to achieve independent living

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[1046] UN Department of Economic and Social Affairs, *Global Status Report on Disability and Development*, at 52.
[1047] UNCRPD Committee, General Comment: para. 15(h); Shakespeare, 'Disability in Developing Countries', 274-277.
[1048] ENIL, 'Barriers to Right to Independent Living', at 41.
[1049] MGLSD, 'Renewed Government Commitment'; NPA, *National Disability-Inclusive Guidelines*, at 16-17; MGLSD, *The National Comprehensive Action Plan on Rights of PWDs 2020-2024*.
[1050] Article 14(1)(g) of the ADP; Also see, General Comment No. 5: para 16(b) and 33.
[1051] Sections 6, 7, 9, 10, 11 and 12 respectively.

PWDs must have access to all the services and facilities as the rest of the population and have the support needed to do this. This entails prohibiting discrimination, adapting or designing services to include disabled people, provision of reasonable accommodations and the availability of support for individuals to access services.[1052]

It is imperative therefore, that these political undertakings are translated into tangible action and not mere rhetoric.

6.1.5. Providing support to families and caregivers of PWMDs

Another critical step that must be undertaken to promote independent living and community inclusion for PWMDs, is for government to provide support to families that have PWMDs in order to lessen the burden of care and to promote community-based living. Globally, families continue to be the primary caregivers to PWDs, especially those with mental disabilities.[1053] Similarly, a study by MDAC and MHU also revealed that in Uganda majority of PWMDs live with their families.[1054] Despite this reality, families caring for PWDs face isolation and stigmatisation from society, and do not receive any support from the government to ease the burden of care.[1055] Yet, besides the disability-related costs and the loss of income for one of its members who becomes a full time or part-time caregiver, disability-related expenses can push the whole family deeper into poverty and cause resentment to caring for a family member with a disability.[1056] Similarly, Simpson and Chipps noted that the lack of community services for families and the burden of caring for a family member with psychiatric problems takes its toll on the family and there is a risk that the human rights of both the family and the mental health care user may be

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[1052] Fox,'What's Fair?!', at 286.
[1053] Inclusion International, 'Global Report on Article 19', at 27-28; ENIL, 'Barriers to Right to Independent Living', at 21.
[1054]MDAC and MHU, 'They don't consider me as a person,' at 15 reported that out of the 40 people interviewed for this study, 20 lived with their parents and siblings, 15 with their spouses and children, 3 with extended family, and 2 on their own.
[1055] *Ibid*, at 80; Verity, Tuhiro and Mutamba, 'Family care for PWSI', at 8.
[1056] ELIN, 'Barriers too Right to Independent Living', at 22; Ojok, 'Mapping and Assessing', at 29; The African Child Policy Forum, 'The Hidden Reality', at 31.

violated.[1057] Therefore, it is essential that families or carers have the resources, knowledge and skills to meet the immediate needs of the PWDs in terms of their physical, emotional and psychological well-being.[1058]

Hence, families need to receive support and should be given comprehensive information about available support services for carers in the community.[1059] These support measures may include: respite care, day-care services, culture and sports programmes, drug benefits and nutritional support, educational programmes, health related supports, equipment and assistive devices, educational assistants, supported employment, personal assistance, residential placements and family training.[1060] The UNCRPD Committee requires State Parties to empower family members to support the family member with disabilities, so as to realise their right to independent living and being included in the community.[1061] Under Paragraph 68, the UNCRPD provides that:

> State Parties should provide adequate support services to family carers, so they can in turn support their child or relative to live independently in the community. This support includes respite care services, childcare services and other supportive parenting services. Financial support is also crucial for family carers who often live in situations of extreme poverty, without the possibility of accessing the labour market. States Parties should also provide social support to families and foster the development of counselling services, circles of support and other adequate support options.[1062]

Therefore, borrowing from the cash transfer programmes for PWDs in Kenya and South Africa, the person with severe disabilities cash transfer Programme in Kenya, and the Social Assistance Disability Grants initiative in South Africa, the Uganda government should design programmes geared towards providing financial support or grants to PWMDs and/ or their families or caregiver, and also ensure that

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[1057] Simpson and Chipps, 'Mental Health Legislation', at 54.
[1058] EEG, 'Common European Guidelines on Transition', at 131.
[1059] *Ibid,* at 132.
[1060] Inclusion International, 'Global report on Article 19', at 79-80.
[1061] UNCRPD Committee, General Comment No. 5: para. 55.
[1062] *Ibid,* para. 68.

they have access to economic empowerment initiatives like the Youth Livelihood Programme, Uganda Women Entrepreneurship Programme, the newly adopted Community Development Fund and the Parish Development Model.[1063]

Currently, the disability grant managed under the MGLSD is not only inadequate for PWDs but also not tailored towards family support. Commendable, however, is government's renewed commitment towards economic empowerment of all PWDs.[1064] This can be leveraged on to achieve the steps suggested above.

6.1.6 Using the Personal Assistants or Support person framework

Establishing a Personal Assistant support framework is another step that the Uganda government should employ in order to meet its objective of promoting community health care and community living for PWMDs. PWMDs often need support to carry out the various daily tasks of life. This support may be provided by a Personal Assistant (PA) who must be chosen and contracted by the PWDs.[1065] According to the UNCRPD Committee, a Personal Assistant refers to person-directed or user-led human support available to a PWD and it is a tool for independent living.[1066] An effective PA system must satisfy a number of criteria including: being competitively funded or remunerated by the State; be contracted based on the needs assessment of the PWDs; and to ensure exercise of control, personal autonomy and choice, the PA must be chosen, trained and instructed by the PWDs; in certain respects, the PA may be used as a tool for supported-decision making as opposed to substituted-decision making.[1067] ENIL contends that Personal Assistance is a system to enable independent living which should be funded by the

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[1063] Charlotte Pearson, 'Independent Living', at 246 notes that the direct cash payment model started in the US in the 1970s.
[1064] MGLSD, 'Renewing Government Commitment', at 16. Also see, Parliament Hansards, dated 12th September 2018, at 28 where Honourable Safia Nalule raised the need to have a provision relating to providing support to women and children with mental illnesses and also families and caregivers of persons with mental illness.
[1065] KNHC and OSIEA, 'How to implement Article 12', at 37.
[1066] UNCRPD Committee, General Comment No.5: para. 16(d).
[1067] *Ibid,* para. 16(d)(i-iv); ENIL, 'Barriers to Right to Independent Living', at 50.

State and take the place of the outdated and abusive system of institutionalisation.[1068]

In advocating for the significance of Personal Assistants in the processes of promoting independent living and community inclusion, the ENIL further opine that:

> Personal Assistance goes beyond community living [Independent living], it is a process where an individual chooses and employs a Personal Assistant to provide support so that the PWD can live independently, thus generating employment for others, contributing to the national income through payment of taxes and giving the option for the individual themselves to be employed. Those with perceived higher support needs can effectively become contributors to society through employment of a team of PAs, instead of perceived drain on the resources while imprisoned in institutions…It is only through personal assistance that financial and humanity gains are maximised for the individual, the community and the economy.[1069]

Therefore, through an effective, accessible and affordable PA system, PWMDs are enabled and supported to live independently in the communities, be healthy, exercise their choice and preferences, and even be economically productive like their non-disabled counterparts.

Unfortunately, the PA framework has neither been utilised by South Africa, Kenya nor Uganda. PWDs often receive support from their informally contracted friends, relatives or concerned person, and they meet the associated costs of the assistance. This inevitably places an additional financial burden on the PWDs, and often hinders their access to services and participation in community activities.

6.1.7 Providing assistive devices

Government should establish a framework to provide assistive devices to PWMDs. Assistive devices are vital for achieving independent living and

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[1068] ENIL, 'Research paper on Community Living', at 260.
[1069] *Ibid*, at 261; Shakespeare, 'Disability Rights and Wrongs', at 139.

participation in society.[1070] Therefore, it is imperative that an individual needs assessment that goes beyond medical needs is conducted for PWMDs to determine one's specific or unique needs.[1071] This is to ensure that services or assistive devices provided are tailor-made to suit the PWMDs, and also enhance the individual's productivity, dignity and autonomy. Such needs assessment may enable the government to determine the relevant support services or assistive device/ technology a PWMDs may require. The term 'assistive technologies' refers to a variety of products and services that allow or make easier the implementation of certain tasks by the user or improve his or her safety.[1072] These technologies are most effective when they are meet the preferences of the user and take into consideration the environment in which they are used or installed.[1073]

It is commendable that all the three countries—Uganda, Kenya and South Africa—have laws that provide for exemption of taxes on assistive devices or technologies. In Kenya, the government has gone further and partnered with NGOs to provide locally manufactured assistive devices to PWDs. Unfortunately, these are limited to only those with physical and visual impairments, hence leaving out those with other forms of disabilities, including PWMDs. By conducting individual needs assessments on her citizens with mental disabilities, Uganda will be able to determine the unique circumstances of each of them and then provide the necessary equipment to enable them enjoy the right independent living and community inclusion.

[1070]Shakespeare, 'Disability in Developing Countries', at 275.
[1071] UNCRPD Committee, General Comment No.5: paras. 15(c), 28 and 63.
[1072]Cowan and Turner Smith, 'The Role of assistive technology in alternative models of care for older persons', cited in *Royal Commission for long term care,* at 325-46, *cited* in EEG, 'Common European Guidelines on Transition', at 90.
[1073] EEG, 'Common European Guidelines on Transition', at 90.

6.1.8 Promoting and supporting self- advocacy and peer support programmes

Another step is for government to embark on programmes that promote self-advocacy and peer-to-peer support. PWMDs require a lot of support and encouragement even from within their own membership. Self-advocacy and peer-to-peer support programmes are pertinent in this regard. Self-advocates refer to PWDs who are enabled to speak up for themselves and have control over their lives.[1074] On the other hand, peer-to-peer support refers to people with a particular experience or background advising and supporting others in a similar situation. The WHO states that peer-support to mental health services consist of one-to-one or group support sessions provided by persons with lived experiences to others who wish to benefit from their experience and support. The aim is to support people on the issues they consider important in their own lives and recovery in a way that is free from judgment and assumptions.[1075] The Expert European Group (EEG) contend that peer support could play an important role in the process of transition from institutional care to community living. Its value lies in the equal relations and the unique experiences and the knowledge of the people involved.[1076] It should be noted that participation in peer support is often based on choice and informed consent.[1077] Hence, peer support is beneficial in restoring dignity and building skills and economic empowerment of PWMDs.

Laudably, like Uganda, both in Kenya and South Africa, DPOs that work with PWMDs provide self-advocacy and peer support programmes to empower their clients with mental disabilities.[1078] Organisations like Mental Health Uganda, Heart Sound Uganda, Mental Health Recovery Initiatives, Uganda Association of Parents of Persons living with Intellectual Disabilities, Triumph Uganda, My Story Initiative

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[1074] *Ibid*, at 130.
[1075] WHO, 'Peer Support', at 2.
[1076] EEG, 'Common European Guidelines on Transition', at 131.
[1077] WHO, 'Peer Support', at 2.
[1078] Ojok, 'Mapping and Assessment', at 35.

(Uganda) are applauded for their support initiatives to PWMDs. Government must collaborate with such DPOs to compliment and inform government efforts towards promoting rights and providing services and programmes to PWMDs.

6.1.9 Provision of alternative housing/ living options

Government must take steps to provide suitable accommodation for PWMDs to avoid homelessness as another step towards promoting independent living and community inclusion. Housing is a basic human need, and adequate and appropriate housing is a key component of establishing and maintaining human wellbeing.[1079] It is argued that housing also plays a key role in whether or not people with mental health problems can make successful transition from institutions to community care or sustain meaningful community living.[1080] The UHRC report confirms that PWDs are among the vulnerable and homeless persons who sleep in sacks on verandas and corridors of different buildings in Uganda.[1081] For some with mental disabilities, institutionalisation in medical facilities or prisons is the norm.[1082] Article 19 (a) of the UNCRPD enjoins States Parties to ensure that PWDs exercise the right to independent living in the community by choosing their own home, where and with whom to live. However, often time PWMDs are not able to exercise their choice on where to stay but remain homeless, institutionalised or live with their families for lack of other options.[1083] In Europe, alternatives like group homes, community homes, supported housing, day-care facilities or dispersed homes are being used to provide alternative housing modes and enable the deinstitutionalisation process.[1084] However, these homes need to be cautiously used so as not to violate the principles of personal autonomy and individual choice, which

[1079]HSE Ireland, 'Addressing the Housing needs', at 4.
[1080] *Ibid*, at 8.
[1081] UNHCR, 21st Annual Report 2018', at 71 (available on file with author); Onoria, 'Guaranteeing right to Adequate Housing', at 26.
[1082] As demonstrated by Komuhanda's story; Also see, the list annexed of PWMDs confined Luzira prison in Uganda.
[1083]UNCRPD Committee, General Comment No.5: para 24-25.
[1084] ENIL, 'Barrier to the Right to Independent Living', at 25.

is characteristic of institutions.[1085] Criticising the group homes, the European Commissioner of Human Rights noted that:

> Group homes often do not differ much from institutions as they restrict the control of the people over their lives and isolate them from the community, despite being physically located within the residential area (or community). Clustering children or adults in communities draws attention to them as a group rather than individuals and sets them apart from the rest of the neighbourhood. In addition, linking support services with housing in group homes limits the choice of the people about where they can live."[1086]

Similarly, ENIL comments that,

> The problem with such contemporary institutions like group homes, is that they group people, based on a single characteristic- the presence of an impairment- and set them apart from the rest of the community, thus perpetuating the isolation and segregation. Thus, even when psychically located in the community, they make genuine engagement in the community impossible…Though downsized to 10-12 people, they remain institutional in character as they restrict the individual's day to day choices. Often residents are not allowed to even make simple decision.[1087]

On the other hand, dispersed homes are apartments and houses of the same size and type as the majority of the population lives in, and are scattered throughout residential neighbourhoods among the rest of the population.[1088] PWDs living in these homes are provided with supported-living from agencies that do not control their accommodation or choices of whom they wish to live with, nor do they have a routine way of life.[1089] The WHO notes that people may require extra support to live independently (supported-living) but these supported-living services should reflect and be responsive to the diverse needs a person may have.[1090]

[1085] UNCRPD Committee, General Comment No.5: para 16(c).
[1086] EEG, 'Common European Guidelines on Transition', at 95.
[1087] ENIL, 'Barriers to independent Living', at 25.
[1088] EEG, 'Common European Expert Guidelines on Transition', at 94.
[1089] *Ibid*, at 94.
[1090] WHO, 'Supported living services', at 2.

As discussed above, residential facilities, protected shelters and day-care facilities are used in South Africa. Kenya and Uganda, however, have no alternative accommodation model and largely practice institutionalised care of PWMDs who cannot live with their families or who are abandoned to wonder about on the streets. It is vital therefore that Uganda provides alternative affordable, adaptable, accessing and quality accommodation or living arrangement or housing for PWMDs with no family support or who wish to live by themselves. The house should be allocated following an individual assessment in order to ensure user-friendliness and provision of the relevant support. Whatever living or housing arrangement is preferred, government must ensure that it does not curtail the rights of PWMDs to exercise their choice and preference, uphold their dignity and individual autonomy.

6.1.10. Increase staffing and adequately train the personnel

Government must take serious steps to recruit and ensure adequate training of staff in the mental health sector. The WHO reveals that there are generally very low levels of staffing in the mental health sector in the African region.[1091] The effective implementation of the provisions in the MHA, 2019 require a vast array of well skilled and adequately facilitated human resources. These personnel may include: community-based mental health workers, social workers, personal assistants, counselling and psychosocial support personnel, medical personnel, and members of the Mental Health Advisory Boards.[1092] Hunt and Mesquita rightly observe that augmenting interventions to ensure equality of opportunity for the enjoyment of the right to health [which includes mental health] will require training adequate numbers of professionals, including psychiatrists, clinical psychologists, psychiatric nurses, psychiatric social workers, occupational therapists, speech therapists, behavioral therapists, and caregivers, in order to work toward the care and full integration of individuals with mental disabilities in the community.[1093]

[1091] WHO, 'Mental Health Atlas 2020', at 61-63.
[1092] Twinomugisha, 'A health and Human Rights Critique', at 16-17.
[1093] Hunt and Mesquita, 'Mental Disabilities', at 345.

Studies by Ojok, Twinomugisha and MDAC MHU reveal the challenge of understaffing in the mental health units in Uganda that affect delivery of CMHCS and also cause staff overload due to the overwhelming demand for mental health care.[1094] To address this challenge, Parliament's Sectoral Committee on Health has called upon government to make deliberate efforts to train and recruit mental health service providers.[1095]

Hence it is imperative that government ensures provision of an increased number of adequately trained personnel coupled with adequate financing and resourcing of all mental health facilities from community to tertiary level so that the mental health units are adequately facilitated to provide the desired services to the people.

6.1.11 Combating poverty through economic empowerment measures of PWMDs

> I am requesting if they [the government] could help us and give us some small jobs so that we can look after our children, because if you go to ask for a job they just chase us away because they know we are 'mad'. So you find that the conditions we are going through are very difficult.[1096]

Government must take steps to ensure that PWMDs are engaged in income generating activities. The high levels of poverty amongst PWDs continues to be a matter of grave concern in the disability discourse.[1097] In its preamble, the UNCRPD highlights the fact that the majority of PWDs live in conditions of poverty, and recognises the critical need to address the negative impact of poverty on PWDs.[1098] Inclusion International reports that in Africa over fifteen million people are believed

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[1094] Ojok, 'Mapping and Assessing', at 26; Twinomugish, 'A Health and Human Rights Critique', at 46; MDAC and MHU, 'Psychiatric hospitals', at 46-48; MDAC and MHU, 'They don't consider me as a person'; Mental Health and Human Rights in Ugandan Communities', (2014) at 12-13

[1095] Parliament of Uganda, *Report of the sectoral committee on Health on Mental Health Bill, 2014*, at 13.

[1096] MDAC and MHU, 'They don't consider me as a person', at 13. Interview with a woman with mental health issues.

[1097] Hanass-Hancock, Nene, Deghaye *et al*, 'These are not luxuries', at 1.

[1098] UNCRPD Preamble, para. (t).

to have intellectual disabilities and majority live in abject poverty, neglect and social isolation.[1099] The right to independent living and community inclusion can be hampered by inability of PWMDs accessing livelihood, economic or employment opportunities. Yet these are vital for economic empowerment, breaking the dependency syndrome, meeting the cost or care and support where needed and realizing their productive potential. A study by Hancock, Nene, Deghaye *et al* revealed that participants with high care and support needs (who are from low-income households) find that living in an institution is often the only financially feasible way of obtaining the care needed to stay alive and safe.[1100]

Poverty hinders disability-inclusion in the community, and in many families is a push factor for institutionalisation, especially in the face of limited government support to the families.[1101] As ENIL notes, inability to cover additional disability-related costs makes mainstream services unaffordable for disabled people and becomes a barrier to inclusion.[1102] Similarly, the European Expert Group in its advocacy for social inclusion observed that

> The closure of institutions and the development of a range of community-based services is only one aspect of the deinstitutionalisation process. Measures should be introduced to make public services, such as health care, education, life and job coaching, housing, transportation and culture, are inclusive, affordable and accessible to all, regardless of their age or impairment. This should be accompanied by actions aimed at alleviating poverty, which is still one of the main reasons for institutionalisation in many countries.[1103]

Ojok's study confirms that PWMDs and their caregivers in Uganda face high levels of poverty since they often have low levels of education, no employment or engage in low income activities, face high costs in accessing mental health care and are often constrained by the burdens of caregiving from engaging in employment or

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[1099] Inclusion International, 'Global Report on Article 19', at 76.
[1100] Hanass-Hancock, Nene, Deghaye *et al,* 'These are not luxuries', at 5.
[1101] Verity, Mutamba, Cappo *et al*, 'Family care for PWSI', at 7-8.
[1102] ENIL, 'Barriers to the Right to Independent Living', at 43.
[1103] EEG, 'Common European Guidelines on Transition', at 67.

other income-generating activities.[1104] To address the need for economic empowerment, Tesemma advocates for the shift from a medicalised paradigm of social welfare and dependency, to the adoption of an independent living paradigm which perceives PWDs as rights holders, with the right to independent living in a barrier free environment characterised by economic self-reliance.[1105]

Therefore, it is imperative that Uganda adopts measures that will promote economic empowerment and poverty alleviation that can be accessed to benefit PWMDs and their families. There is no evidence to confirm that the current Community-Based Rehabilitation Grant, or the economic empowerment programmes in Uganda such as the Youth Livelihood Programme (YLP), Uganda Women Entrepreneurship Programme (UWEP), the Disability grant, the newest National Special Disability Grant and the Parish Development Model administered by the MGLSD have been accessed by PWMDs or their families or caregivers.[1106] The sheltered and protective workshops in South Africa and Kenya may be a good approach, but these may, to some extent, isolate PWMDs from interaction and inclusion in mainstream work space. Hence, the need to ensure promotion of reasonable accommodation measures in access to livelihood support and economic initiatives and employment of PWMDs and their caregivers.[1107] These measures should be accompanied with interventions that strengthen opportunities that promote the right to education and employment for PWMDs.[1108] In so doing, government will meet its aspirations of promoting inclusion and participation of PWDs in economic and development programmes.[1109]

[1104] Ojok, 'Mapping and Assessing', at 29; Verity, Turiho, Mutamba *et al*, 'Family care for PWSI', at 7-8.
[1105]Tesemma, 'Economic discourse', at 145.
[1106]Presentation by the MGLSD National Coordinator Community-Based Rehabilitation at disability Research validation seminar held in June 2019 at the School of Law, Makerere University.
[1107] NUDIPU, 'Disability-Demand', at 14-17.
[1108] MDAC and MHU, 'They don't consider me as a person', at 34-36.
[1109] MGLSD, 'The National Comprehensive Action Plan on the Rights of Persons with Disabilities 2020-2024', Objective 5.

6.1.12 Engaging in legal reform

Government must engage in a process of legislative reform and repeal all laws that perpetuate the stigmatisation of PWMDs and deny them their human dignity, individual recognition and autonomy.[1110] Arguably, legal provisions that use derogatory language tend to traumatise, humiliate and stigmatise PWDs hence resulting into disablement, exclusion and violation of their dignity.[1111] There exists laws that not only curtail the legal capacity of PWMDs, but also perpetuate their marginalisation, stigmatisation, disempowerment and isolation in society.[1112] There is an enormous call for reform of all laws that perpetuate stigmatisation, marginalisation and disablement of PWDs generally and particularly those with mental disability.[1113] In *Purohit and Mooore v The Gambia*, the African Commission called on State parties to ensure reform of all their domestic laws and bring them in conformity with the ACHPR.[1114] Bartlett, Jenkins and Kiima have also reinforced the need to reform laws that focus on institutionalisation of PWMDs to recognise the paradigm shift towards the provision of CMHC and support services as propelled by the UNCRPD.[1115]

In addition, Article 4 of the CRPD and Article 4(c) of the ADP enjoins States to pass legislation that promotes the rights of PWDs and modify discriminatory laws. Legislation must support the full inclusion and participation of different groups in society. As further noted by Naggita,

> It is thus imperative that great care and attention is given to the law since it can be both an enabler and a disabler. And by necessity this

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[1110] UNCRPD Guidelines on Deinstitutionalisation: under para 53, the Committee calls on States to repeal laws and regulations, and modify or abolish customs and practices that prevent persons with disabilities from living independently and being included in the community.
[1111] Naggita, 'The Solution is the Problem', at 58; Inclusive International, 'Global Report on Article 19', at 65-67.
[1112] UNCRPD Committee, General Comment No. 5, para. 15(a).
[1113] Hunt and Mesquita, 'Mental Disabilities,' at 336; Simpson and Chipps, 'Mental health Legislation', at 50; *CEHURD and Iga Daniel v The Attorney General*, Constitutional Petition No. 64 of 2011.
[1114] Communication No.241/2001; Similarly, *Marlon James Noble v Australia, Communication* N0.7/2012 in which the UNCRPD Committee called on the State to reform the Mental Impaired Defendants Act which was found to be discriminatory.
[1115] Bartlett, Jenkins and Kiima, 'Thinking about Africa', at 2.

> includes the words and language that the law uses…the derogatory labels and language within our laws have the effect of subordinating or legitimating the subordination of people with disabilities. They perpetuate the historical imbalances and marginalisation that people with disabilities have encountered and continue to face, leading to further isolation and exclusion from participation in the affairs of their communities.[1116]

Commendably, Uganda recently adopted a more progressive PWD Act, 2020 and MHA, 2019 that guarantee protection of the fundamental rights and freedoms of PWDs and PWMDs respectively. In addition, the Ugandan judiciary has also risen to the occasion and declared the use of derogatory language like 'idiots', 'lunatics' or 'persons of unsound mind' in reference to PWMDs even in the law unconstitutional.[1117] Remarkably, from the analysis in the Chapter Five, it is evident that the mental health legislation of South Africa, Kenya and Uganda has undergone reform and adopted the use of less derogative language in reference to PWMDs.

6.1.13 The recognition of Legal Capacity of PWMDs

Government must adopt laws and measures that recognise legal capacity for PWMDs. As alluded to earlier, legal capacity is the ability to make one's own decisions and to have these decisions respected in law. It affords autonomy and dignity to all people in how they live and it is essential if people are to achieve the ideals of independent living and community participation.[1118] Often, the non-recognition of PWMDs as equal persons before the law with equal rights like their non-disabled counterparts persists.[1119] This is evident in laws and practices that for instance refer to PWMDs as lunatics, persons of unsound mind with no capacity to contract or even celebrate a marriage, or hold public office, or by guardianship that promote substituted-decision making as opposed to supported-decision making.[1120] ENIL contends that the non-recognition of legal capacity of PWDs is one of the major

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[1116] Naggita, 'The Solution is the problem', at 72.
[1117] *CEHURD and Daniel Iga v Attorney General*, Constitutional Petition No. 64 of 2011.
[1118] Fox, 'What's Fair', at 286; NUDIPU, 'Consultative meeting on the Mental Health Bill, 2014', at 5.
[1119] Inclusion International, 'Global Report on Article 19', at 57; WHO, 'Guidance on community mental health services', at 6-7; MDAC and MHU, 'They don't consider me as a person', at 18-19.
[1120] UNCRPD General Comment No. 5: para 15(a).

barriers to realising Article 19 of the UNCRPD as well as other interconnected provisions in the Convention.[1121] The recognition of legal capacity is therefore paramount in upholding the dignity and permitting PWMDs to make their own decisions pertaining to their lives like their non-disabled counterparts. As Fox opines,

> If people's rights to make decisions is not respected in law, then it becomes almost impossible for them to exercise their rights to independent living. And if people are denied opportunities to have independent lives, how then can they develop the skills or acquire the experience they need to make good decisions and develop independent living skills.[1122]

Inclusion International also argues that the right to decision making is intertwined with the right to live in the community and these two rights must be read together.[1123]

Laudably, section 60 (1) of the MHA, 2019 recognises that a PWMDs have the right to enjoy legal capacity on an equal basis with others in all aspects of life. Hence, the recognition of all PWDs as equal persons before the law in accordance with Articles 12 of the UNCRPD and 7 of the ADP is fundamental to promoting the right of PWMDs to independent living and community inclusion.[1124] This is because, with the necessary support, a PWMD will be able to engage in various aspects of community life, including: executing contracts; solemnising a valid marriage; having parental rights over their children; enjoying family life; undertaking employment; and even accessing justice in their own right in case of any human rights violation, among others.

[1121] ENIL, 'Barriers to the Right to Independent Living', at 44.
[1122] Fox, 'What's Fair', at 358.
[1123] Inclusion International, 'Global report on Article 19', at 59.
[1124] UNCRPD General Comment No. 5: para 27 and UNCRPD General Comment No.1 of 2014.

6.1.14 Combating stigma and discrimination through community awareness and sensitization

Government must take steps to enhance awareness and address the persistent high levels of stigma and discrimination faced by PWMDs. As discussed above, negative societal attitudes and prejudices continue to fuel stigma, discrimination and marginalisation and institutionalisation of PWMDs both at community and family level in Uganda.[1125] The Parliament's Sectoral Committee on Health observed that:

> Stigma surrounding mental health and its treatment is one of the greatest barriers to mental health care. It causes discrimination, deprivation and exclusion of individuals and reduces access to care by individuals who need it. Despite the high prevalence of mental illness in Uganda, previous studies have consistently demonstrated that stigmatisation of the mentally ill is still highly prevalent and not only by the general population but also by health providers.[1126]

In concurrence with the above finding, Kabale testified before the same Committee and stated that:

> Lack of information in the community about mental health leaves a very big gap where the population remains with false misconceptions, myths and fears about the illness and the thinking that such affected persons are cursed by gods, have been bewitched, and others to think that such persons suffering from mental illness committed very offensive and aggravated sin and now society feels it is worthy for them to go through every kind of suffering in their whole life to pay for the wrong they did or their grand forefathers. This is a very wrong attitude of the society due to lack of information about mental health and lack of accessible services at the community level.[1127]

Such societal attitudes create barriers to access to services and hinder the enjoyment of the right to independent living and community inclusion.[1128]

[1125] Mugisha, Ssebunya, Hanlon *et al*, 'Mental health service users', at 7; MDAC and MHU, 'They don't consider me as a person', at 12-14.
[1126] Parliament of Uganda, 'Report by sectoral committee on Health on the Mental Health Bill, 2014,' at 11; MDAC and MHU, 'They don't consider me as a person', at 19-22.
[1127] Kabale Benon, 'Submission to the Health Committee in Parliament', at 3; Kabale, 'Personal Experience' at 1; Kabale, 'A Critical Overview', at 1.
[1128] UNCRPD Committee General Comment No. 5, para 15(f).

Commenting on the impact of stigma on PWMDs, Orovwuje *et al* observe that "invariably the mentally ill persons encounter rejection and humiliation that are in some way tantamount to a 'second illness' which bars their enjoyment of various aspects of life, consequently leading to neglect of themselves and their diet, and frequently even delay seeking treatment."[1129]

Community prejudices against PWMDs may also affect their dignity, sense of empowerment as well as their family's ability to care for them, and in some cases may result in institutionalisation.[1130] Besides, once deinstitutionalisation is underway, stigma will hinder full inclusion and participation in the community of PWMDs and can even lead to discrimination and violence.[1131] Advocating for the need to combat community prejudices and stigma, Inclusion International noted that:

> It's about building the capacity of communities to understand how supports can be provided so that all persons with disabilities, regardless of perceived level of support need, are able to make their own decisions and have the decisions respected and [live independently and be included in the community].[1132]

To address stigma and its negative ramifications, the Parliament's Sectoral Committee on Health recommended that the government allocates resources for mobilisation and sensitisation of the communities on mental health care services, and also work towards eliminating discrimination, deprivation and exclusion of individual's access to mental health facilities and services.[1133]

Hence, Uganda needs to deepen its public sensitisation and community awareness drive to enhance knowledge and information about PWMDs, the existing laws and policies that protect the rights of PWDs, the available economic

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[1129] Orovwuje and Taylor, 'Mental health consumers, Social justice and the Historical antecedents of Oppression', cited by Swanepoel, 'Mentally ill in South Africa', at 3.
[1130] Hunt and Mesquita, 'Mental Disabilities', at 349.
[1131] EEG, 'European Common Guidelines on Transition', at 133.
[1132] Inclusion International, 'Global report on Article 19', at 61.
[1133] Parliament, 'Sectoral Committee on Health Report', at 12.

empowerment initiatives and procedures of access, the availability of CMHC and support services, and the deinstitutionalisation strategy once developed. This information will not only empower PWMDs but also improve community's response and support to PWMDs.

6.1.15 Removal of societal barriers

In addition to combating stigma, governments should take steps to eliminate societal stigma and create a disability-friendly environment that allows even PWMDs to thrive and enjoy the right to independent living, community inclusion and participation. Article 35 of the Uganda Constitution, 1995 requires both State and non-State actors to institute measures that ensure that PWDs realise their full potential in society. Such measures involve comprehensive interventions that focus on the removal of social, legal, economic, attitudinal and environmental barriers that perpetuate exclusion and marginalisation of PWDs in society. According to Naggita,

> Removal of barriers would enable PWDs to take their rightful place in society, thus lifting them out of the gutters and poor ghettos where they are literally and figuratively located. They would then be able to contribute to the economic and other development of the country. This would not only translate into less dependency on their families and other caregivers, but would also relieve and free them and their caregivers to participate more fully at all levels in society.[1134]

Negative societal attitudes, coupled with the inaccessible environment, are key factors that lead to exclusion and marginalisation of PWMDs in Uganda. Hence, in accordance with Article 8 of the UNCRPD, the government must sensitise the people about the rights of PWMDs, combat stigma and provide a disability-friendly environment that allows PWMDs with the needed support to thrive, and exhaust their full potential on equal basis with others.[1135]

[1134] Naggita, 'The State and the Law', at 205; Kabale, 'Personal Experience', at 3; Kabale, 'A Critical Overview' at 1.

[1135] Article 8(1) enjoins State Parties to adopt immediate, effective and appropriate measures: a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities; b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and

6.1.16 Enhance Access to justice for PWDs

Government is enjoined to create disability-friendly judicial system so as to enhance access to justice for PWMDs. Access to justice refers to the ability to seek and obtain redress for wrongs through institutions of justice, formal or informal, in conformity with human rights standards.[1136] The study by MDAC and MHU found that many PWMDs were unable to access justice in case of violations, either due to fear, stigma, cost of litigation and ignorance of the redress mechanisms.[1137] The UNCRPD Committee enjoins States Parties to ensure access to justice and provide legal aid, appropriate legal advice, remedies and support, including through reasonable and procedural accommodation for PWDs who seek to enforce their right to living independently in the community.[1138] This calls for enhanced and disability-friendly access to justice systems that allow PWDs and in particular PWMDs to seek redress for any rights violations.

Legislatively, the Uganda Constitution, 1995,[1139] and the MHA, 2019[1140] guarantee the right to access to justice for an effective legal remedy in case of any rights violation. This should then be buttressed by a body of competent judicial officers and members of the quasi-judicial mental health board, who are conscious about the plight of PWDs. Fox argues that, allied to the issue of legal capacity and independent living, is the need to ensure access to justice systems for PWIDs because the ability to resort to court to exercise rights is a core ingredient of anti-discrimination laws [and practices].[1141]

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age, in all areas of life; and (c) To promote awareness of capabilities and contributions of persons with disabilities.

[1136] United Nations General Assembly, Human Rights Council Resolution: A/HRC/27/65, 'Access to Justice in the Promotion and Protection of the rights of Indigenous peoples: Restorative justice, indigenous judicial systems and access to justice for indigenous women, children, youth and person with disabilities.' para. 5.

[1137] MDAC and MHU, 'They don't consider me as a person', at 25-26.

[1138] UNCRPD Committee Gen Comment No.5: Para 67.

[1139] Article 50-53.

[1140] Section 14.

[1141] Fox, 'What is Fair?!', at 359.

6.2 Conclusion

From the foregoing discussion, it is clear that there are a number of practical strategies that Uganda can employ to enable PWMDs access mental health services, realise their right to independent living and community inclusion, and also live with human dignity. Worth noting is that with the relevant support afforded to PWMDs, they can live independently in the community and be productive. Like other State Parties to the UNCRPD, Uganda is enjoined to take all necessary legislative, policy and programmatic measures to domesticate the provisions enshrined in the Convention.[1142] Therefore, the ball is in Uganda's court to make good on its undertakings and avert the state of despair for her citizens with mental disabilities suffering unwarranted institutionalisation, abandonment, neglect, exclusion or even death as demonstrated by the testimonies of Kabale, Kamuhanda Mwase and Mudoola. If the above identified strategies are adopted and effectively employed, Uganda will boast of also fulfilling its mandate not only under the UNCRPD, ADP (when ratified), UNCRPD Guidelines on Deinstitutionalisation, but also Article 35 of her own Constitution, the renewed government commitment towards disability inclusion and mainstreaming, the National Comprehensive Action Plan on the Rights of PWDs 2020-2024, and the SDGs principle of leaving no one behind.

As discussed earlier, Uganda has no mental health policy. Yet, it is argued in this thesis that the strategies identified must be embedded within a policy framework to enable effective implementation and realisation of Uganda's aspirations. Therefore, Uganda must adopt a robust policy framework setting benchmarks as discussed in the next chapter.

[1142] Article 4 of UNCRPD and Article 4 of the ADP.

CHAPTER SEVEN

RECOMMENDATIONS AND CONCLUSION

Uganda government should walk the talk and take mental health seriously.[1143]

7.1 Introduction

The discussion in the preceding chapters have confirmed that PWMDs in Uganda still live in situation of marginalisation, discrimination, isolation and exclusion from participation in society. This state of affairs prevails despite the fact that Uganda has many progressive laws that seek to guarantee the protection of the rights of PWMDs. Furthermore, the mental health sector is in dire need of reform to transition from over institutionalisation to provision of CMHCS and support services to enable PWMDs access mental health care services from within their communities, as well as realise and enjoy the right to independent living and community inclusion. The testimonies of Kabale, Kamuhanda, Mwase and Mudoola demonstrate the plight of PWMDs in Uganda. Drawing lessons from South Africa and Kenya, Chapter Six identifies several strategies that can be adopted by Uganda to promote independent living and community inclusion for PWMDs.

However, these strategies should not be introduced in a piecemeal fashion. Instead, the government must lead, direct and guide the implementation of the strategies by establishing a clear and robust policy framework in which they will be anchored. This will also provide a holistic approach to promoting and protecting the rights of PWMDs and fit within the goal of the National Comprehensive Action Plan on the Rights of PWDs 2020-2024. This final chapter examines some aspects of this overarching policy framework and makes recommendation on how it can be achieved.

[1143]Twinomugisha, 'A Health and Human Rights Critique', at 46; MDAC and MHU, 'They don't consider me as a person', at 37-43.

7.2 Recommendations

7.2.1 Establish a clear and robust policy framework

According to Hunt, more than 40 per cent of the countries have no mental health policy and over 30 per cent have no mental health programmes. Over 90 per cent of the countries have no mental health policy that includes children and adolescents. In short, mental health is the most grossly neglected element of the right to health.[1144] Hence, the government must have the political will to adopt a clear and robust policy framework that will facilitate and guide the implementation of the practical strategies identified in Chapter Six and ensure the protection of the rights of PWDs. As Flynn rightly argues, political leadership is a crucial factor in ensuring successful implementation, whether of an international convention or domestic policy.[1145] Further, that leadership from the government perspective is probably best expressed in the political will to achieve change, to listen to PWDs, and to put in place structures, laws, policies and programmes that advance the rights of citizens with disabilities.[1146] Similarly, Fox contends that achieving independent living and community inclusion for PWDs requires more than legislative and structural changes. It requires a decisive political commitment and leadership endorsing and actively supporting the rights of all disabled people to live independently and participate in their communities.[1147]

Indeed, the political choices of the Uganda government are crucial to the realisation of their political commitments.[1148] To reiterate Degener and Quinn's assertion that,

> A key element of a more integrative and inclusive approach to disability, was premised on the realisation that exclusion and segregation of PWDs do not logically follow from the fact of

[1144]Hunt, 'Special Rapporteur Report on everyone to the enjoyment of highest standard of health,' at 379.
[1145] Flynn, *From Rhetoric to Action*, at 201.
[1146] *Ibid*, at 201.
[1147] Fox, 'What's Fair', at 190.
[1148] Ojok, 'Mapping and Assessment', at 39.

> impairment, but rather results from political choices based on assumptions about disability.[1149]

Consequently, the Parliament's Sectoral Committee on Health has called on government to adopt a mental health policy.[1150] It emphasized that,

> Government should adopt the WHO best practices in the management and governance of mental health service delivery by ensuring global governance through policies and practices that promote equitable health systems as defined by the WHO.

Therefore, the desired robust policy framework could comprise the various aspects as proposed below.

7.2.2 Commit to ratify the ADP and adopt appropriate measures

As earlier noted, Uganda has not yet signed nor ratified or acceded to the ADP. This is a critical gap in the advancement of the rights of PWDs in Uganda and on the African continent. It is undoubtable that to realise the rights of PWMDs, the political leadership must be committed in adopting and implementing legal, policy and programmatic measures that are geared towards meeting the aspirations in the UNCRPD and the ADP.

Commendably, the Uganda government has renewed her commitment towards promoting and protecting disability rights and disability inclusion.[1151] Hence, it is imperative that it ratifies the ADP to reinforce and demonstrate its political commitment at a continental level. If that is done, the government must then adopt measures to translate the rhetorical commitments into reality to achieve the desired social transformation in the lives of PWMDs.

[1149] Degener and Quinn, 'A Survey', at 1-50.
[1150] Parliament, 'Sectoral Committee on Health Report', at 20.
[1151] MGLSD, 'Renewed Government Commitment'; NAP, 'Disability-Inclusive Guidelines'; MGLSD, 'National Comprehensive Action Plan for PWDs 2020-2024.'

7.2.3 Effective implementation of progressive law

Uganda is not void of progressive legal framework and court jurisprudence that advance the protection and promotion of the rights of PWDs generally. In its policy framework, Uganda must commit to implementing the progressive laws and policies with the relevant programmatic action. Fox rightly asserts that law is only effective if it is implemented. If the policies and practice are not compliant with the law, then the law is worthless.[1152] Likewise, Bartlett and Hamzic state that,

> Laws are irrelevant unless they are properly implemented. Far too frequently in African countries, mental health laws-some good - some not so good, are simply not put into practice…While better practice is obviously preferable, actually implementing the minimum standard, or something between the minimum standard and best practice, is almost certainly better than legislating but failing to implement high standards. A plan for implementation should be commenced concurrently with the legislative drafting process.[1153]

In Uganda's context, non-compliance and lack of implementation of the existing laws have been identified by various scholars and activists as a major lacuna in the protection and promotion of rights of PWMDs generally.[1154]

In addition, government must adequately fund the various departments mandated to ensure the effective implementation of the laws. Inadequate funding and resourcing hamper the ability to effectively implement programmes that promote and protect the rights of PWDs through legal front. As Naggita correctly asserts, the lack of resources to implement legal and other interventions is one of the factors which negatively affects the effective implementation of the laws and policies for the betterment of the lives of PWDs.[1155] Hence, adequate resourcing of the various implementation agencies as well as DPOs is a vital tenet in achieving the

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[1152] Fox, 'What is Fair?!', at 343; UNCRPD Guidelines on Deinstitutionalisation; para 60-62.
[1153] Bartlett and Hamzic, 'Practical Tips and Suggestions', at 11.
[1154] MDAC and MHU,' Psychiatric hospitals', at 48; Ojok, 'Mapping and Assessing', at 37; Twinomugisha, 'A Health and Human Rights', 46; Naggita, 'The Solution is the Problem', at 63; NUDIPU, 'Disability Demands', at 10.
[1155]Naggita, 'The State and the Law', at 202-203.

desired government aspirations. The need to commit to provide adequate funding to address the challenges in the mental health sector is discussed in more detail under part 7.2.6

7.2.4 Enhance participation, consultation and inclusion of DPOs and PWDs

In developing a robust policy framework, government must involve PWMDs. It is also pertinent that it involves them in the planning, designing and implementation process of all its policies and programmes that are geared towards promoting and protecting the rights of PWMDs. Here, the popular slogan 'Nothing About us, without Us' needs to be vehemently reiterated.[1156] Bate and Davis argue that the way in which people with learning disabilities are perceived by others can be even more important to their capacity to contribute to the development of social capital and their own social inclusion than their disability.[1157] The WHO reports that globally government's efforts towards collaboration with mental health users, their families or caregivers is very low.[1158] It is therefore crucial that the DPOs, PWMDs and caregivers/ families are involved, included and participate in the discussions, design and development of policy framework, the CMHCS model, as well as the independent living and community inclusion strategies.[1159] Their perspectives must be taken into account so as to acquire legitimacy and adopt user-friendly, acceptable and affordable strategies.[1160] The UNCRPD recognises the relevance of the lived experiences of PWDs in meeting the aspirations of the UNCRPD.[1161] Hunt and

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[1156] Callus and Camilleri-Zahra, ''Nothing About us without Us', at 8-9.

[1157] Bate and Davis, 'Social capital, Social inclusion', at 199. They opine that although social capital has a fluid meaning, social inclusion means ensuring that people with learning disabilities have full and fair access to activities, social roles and relationships directly alongside the non-disabled citizens.

[1158] WHO, 'Mental Health Atlas 2020', at 48; UNCRPD Guidelines on Deinstitutionalisation, para 34-36.

[1159] Mugisha, Ssebunya, Hanlon *et al*, 'Mental health service users', at 2; Inclusion International, 'Global report on Article 19', at 24-27; Ojok 'Mapping and Assessment', at 35; Verity, Turiho, Mutamba *et al*, 'Family care for PWSI', at 7-8.

[1160] UNCRPD Preamble, para (0) notes that, considering that PWDs should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them.

[1161] UNCRPD Preamble, para (m) states that, recognizing the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities, and that the promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and full participation by PWDs will result in their enhanced sense of

Mesquita rightly state that, involving mental healthcare users, their families, and representative organizations, and encompassing their perspectives in the design and implementation of all relevant initiatives helps to ensure that the needs of PWMDs are met.[1162] Flynn also cautions that, in the process of consultation and participation, those consulting must be receptive and willing to seriously listen to the ideas of those being consulted. This is to ensure that consultation is not viewed merely as an exercise but as a genuine opportunity for gaining unique insights on how laws and policies affect individuals in their daily lives, and this requires a willingness to change based on information received.[1163]

By engaging DPOs, PWMDs and their families, the government would be conforming to Article 33(2) of the UNCRPD[1164] and Articles 22 and 33(c) of the ADP. So, measures must be adopted to ensure that voices of PWMDs are heard in developing a society that is inclusive for all.[1165] Lessons from Kenya demonstrate good partnerships between the government and the Non-governmental Organisations (NGOs) in developing devices and implementing policies and programmes.

7.2.5 Effective Coordination between Government agencies

The government policy framework must also emphasize the commitment to coordinate with other government agencies to realise the vision and objectives of the policy. The WHO emphasizes that that implementation of mental health policies, plans and laws requires collaboration between multiple sectors. This includes a country's ministry of health partnering within and beyond the health sector in order to develop a people-centred system, improve the coordination of services and the

belonging and in significand advances in the human, social and economic development of society and the eradication of poverty.

[1162] Hunt and Mesquita, 'Mental Disabilities', at 351.

[1163] Flynn, *Rhetoric to Action*, at 210.

[1164] Article 33(3) states that civil society, in particular PWDs and their representative organisations, shall be involved and participate fully in the monitoring of compliance with the Convention.

[1165] Njoroge, Murangira and Lang, 'Mainstreaming the Rights of PWDs', at 142.

implementation of programmes, and strengthen mental health care pathways.[1166] From the discussion, it is clear that government has the political will to promote disability mainstreaming and inclusion in all its sectors. However, the effective implementation of the progressive laws, policies, programmes and budgets calls for effective coordination and collaboration between the various Ministries, Departments and Agencies (MDAs) and other entities like the Uganda Human Rights Commission (UHRC), the Equal Opportunities Commission (EOC), the National Planning Authority (NPA), the National Council for Disability (NCD), and the newly established Mental Health Advisory Board. Parliament's Sectoral Committee on Health has also urged the government to adopt a multi-sectoral approach to enhance collaboration with Development Partners to undertake mental health promotion and disease prevention interventions.

The government must ensure that these national entities are adequately supported with both the human and financial resources, and decentralised across the country for easier access by PWDs generally. This will enable a holistic approach towards disability mainstreaming of all sectors to promote disability inclusion. Decisions made by these bodies as quasi-judicial bodies should also be respected and upheld by all government entities, officers, NGOs and individuals. After all, the duty to protect and promote the inherent rights of all persons is placed by Articles 17 and 20 of the Uganda Constitution, 1995 on all government and non-government institutions, as well as on all persons.[1167] Hence, the community as a whole must not be forgotten since even the UNCRPD also recognises the role of the community in meeting the standards set out in the Convention.[1168]

[1166] WHO, 'Mental Health Atlas 2020', at 46.

[1167] Article 17(1) provides that it is the duty of every citizen of Uganda: (b) to respect the rights and freedoms of others; (c) to protect children and vulnerable persons. Also see, Article 20(2) The inherent rights and freedoms of the individuals and groups enshrined in this Chapter shall be respected, upheld and promoted by all organs and agencies of government and by all persons.

[1168] CRPD Preamble, para. w states that 'realising that the individual, having duties to other individuals and to the community to which he or she belongs, is under a responsibility to strive for the promotion and observance of the rights recognized in the International Bill of Human Rights.'

7.2.6 Increase resourcing and funding of the mental health sector

The robust policy must also commit to reducing the funding gap in the mental health sector. The WHO affirms that the availability of financial resources for mental health is critical in developing, implementing and maintaining mental health services and making progress towards programme goals.[1169] Inadequate funding of the mental health sector remains a global problem, particularly in Africa.[1170] It should also be noted that increased funding of mental hospitals without enhancing funding for CMHCS, hampers deinstitutionalisation process. The WHO Atlas reveals that globally 70% of government expenditure on mental health was allocated to mental hospitals in upper and lower middle-income countries, compared with 35% in high-income countries. This possibly reflects a situation where centralized mental hospitals and institutional in-patient care still represent the main cost for mental health services, which shows that there is an urgent need for deinstitutionalisation.[1171]

It is clear from the context of South Africa, Kenya and Uganda that the mental health sector is under resourced. From the various literature reviewed, limited funding was raised as one of the key barriers to the provision of mental health care.[1172] In a study by Mugisha, Ssebunya, Hanlon *et al*, mental health service users identified low funding of the mental health sector as one of the barriers to the provision of mental health care.[1173] In concurrence with this finding, Ojok opines that, funds are needed to facilitate mental health units in regional referral hospitals to be able to provide community-based mental health services like out-reaches, sensitisations, distribution of drugs on a regular basis.[1174] Inadequate funding poses

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[1169] WHO, 'Mental Health Atlas 2020', at 51.
[1170] *Ibid,* at 52-54; WHO, 'Pyramid Framework', at 1.
[1171] *Ibid,* at 54.
[1172] WHO, 'Mental Health Atlas' recognises that for many developing countries, including Uganda, less than 1% of the health budget is directed to mental health; Kigozi, Kizza, Ssebunya, Greene *et al* 'A Situation Analysis', at 65; Mugisha, Ssebunya, Hanlon *et al,* 'Mental health service users', at 2.
[1173] Mugisha, Ssebunya, Hanlon *et al*, 'Mental health service users', at 7.
[1174] Ojok, 'Mapping and Assessing', at 37; MDAC and MHU, 'Psychiatric hospitals', at 44-45; Twinomugisha, 'A Health and Human Rights Critique', at 4; Kabale, 'Personal Experience,' at 4.

a great challenge to ensuring availability, accessibility and affordability of quality mental health care services. It also promotes institutionalisation since inadequate funding inhibits the provision of CMHCS and support services and leads to staff demotivation.[1175] Insufficient funding also causes staff demotivation, hence perpetuating negative attitudes and stigma towards PWMDs.[1176] Twinomugisha reminds us that a poorly financed mental health sector renders the mental health workers and other practitioners demotivated and with very limited options and merely emphasize on medicalisation of PWMDs.[1177] Therefore, sufficient financial resourcing of the mental health sector must be key on the government agenda.[1178] To ensure this, I re-echo Twinomugisha's assertion that, 'government should take mental health seriously'.[1179] Providing funding is evidence that government supports the policy and invests in the policy framework.

7.2.7 Accurate data collection

Uganda cannot build and implement an effective policy if it does not have the relevant, reliable and update data in relation to PWMDs. The WHO notes that data collection and reporting in the mental health sector remains a challenge for many countries.[1180] Article 31 of the UNCRPD and 32 of the ADP enjoins States Parties to collect appropriate information—including statistical and research data—to enable them to formulate and implement policies and programmes to give effect to the conventions. Inaccuracy or unavailability of statistical data in relation to PWDs generally and PWMDs in particular is a problem in all the three countries. For instance, Uganda's 2014 National Census Report had no statistical information on PWMDs in the country. Furthermore, in relation to government's economic empowerment programmes under the MGLSD, there is no conclusive data outlining

[1175] Bartlett, Jenkins and Kiima, 'Thinking about Africa', at 5; WHO, 'Pyramid Framework', at 1-2; WHO, Guidance on Community Mental Health Services', at 9-10.
[1176]Docrat, Besada, Cleary *et al*, 'Cost, Resources and Constraints in South Africa', at 716.
[1177]Twinomugisha, 'A Health and Human Rights Critique of the MHA, 2019', at 17.
[1178] Parliament, 'Sectoral Committee on Health Report', at 23.
[1179] *Ibid*, at 46.
[1180] WHO, 'Mental Health Atlas 2020', at 17-18.

the level of access to the grants and programmes by PWMDs, let alone the various categories of PWDs accessing these grants.[1181] The Ministry of Health Information System is still inadequate in capturing information relating to mental health care and institutionalisation.[1182] It is no wonder therefore, that there is a paucity of data in relation to the level of institutionalisation or duration of hospital-based care for PWMDs in Uganda. The Parliament Sectoral Committee of Health observed that:

> While mental illnesses are on the rise in Uganda, a lack of or very little statistical data on the national prevalence of various mental illnesses in the country is not helping the situation…The Ministry of health should consider carrying out mental health survey and integrate Mental Health service data into the National Health Planning.[1183]

Therefore, data collection tools and systems must be developed to gather disability disaggregated data with more accuracy. This data is also essential for planning, establishing and implementing Uganda's policy framework.

7.2.8 Continued Judicial Activism and Public Interest Litigation

Judicial activism puts pressure on the government to change, implement and improve the policy. On the other hand, through public interest litigation, government is held accountable to the populace for its actions and inactions that also have a bearing on the policy framework. Public interest litigation (PIL) refers to court action that seeks to secure the human and constitutional rights of a significantly disadvantaged or marginalised individual or group.[1184] Judicial activism, on the other hand, connotes a judiciary that is awake to the social justice and human rights needs of the society and creative enough to deliver judgements that transcend the letter of the law alone in order to deliver meaningful justice and

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[1181] Presentation by the National CBR Coordinator MGLSD at the disability research validation seminar.
[1182] Dr. Hafsa Sentongo, Acting Commissioner Mental Health Desk, Ministry of Health, statement during the National celebration of the International Mental Health Day on 13th October 2021 under the theme 'Mental Health in an Unequal World': tagline 'Mental Health for All: Leaving no one Behind' at Golden Tulip Hotel, Kampala, Uganda.
[1183] Parliament, 'Sectoral Committee on Health Report', at 8.
[1184] Oloka-Onyango, '*When Courts Do Politics*', at 10.

transformation.[1185] The level of judicial activism so far demonstrated by the courts in Uganda in upholding the rights of PWDs in a number of PIL cases is applauded and encouraged.[1186] Furthermore, for PIL and judicial activism to thrive, the government needs to ensure adequate financing of the judiciary, restructuring of inaccessible buildings, providing information to litigants with disabilities in an accessible format, presence of sign language interpreters, the training of the judiciary to enhance their capacity, competence and knowledge in disability law and rights and provide reasonable accommodation measures for PWDs in the justice system.

As demonstrated in the cited cases, PWDs must also be empowered to engage in PIL to test the applicability and enforcement of the progressive laws, policies and advance their inherent fundamental human rights. It is vital however, that PWMDs themselves are aware of their rights before they can be able to enforce them. This calls for robust sensitization and enhancing awareness of PWD rights to both the individuals with disabilities and the community.

7.3 Conclusion

All persons, including PWDs who are part of the human race, are born free in dignity and right and must enjoy all the fundamental rights and freedoms enshrined in the various progressive international, regional and domestic legislations afore discussed.[1187] Unfortunately, as deduced from the existing literature, this study confirms that even in these contemporary times, many PWDs continue to live in situations of stigmatization, marginalisation, discrimination, abject poverty and exclusion from society, amidst a vast array of progressive international, regional and domestic legal frameworks and court jurisprudence. This deplorable state of affairs

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[1185] Twinomugisha, 'A Health and Human Rights Critique', at 46-47; Naggita, 'The Solution is the Problem', at 74-75.

[1186] *CEHURD and Iga Daniel v The Attorney General*; *CEHURD and Kabale Benon v The Attorney General*; *Bushoborozi Eric v Uganda* HCT-01-CV-MC-11 OF 2015; CEHURD, *Perez Mwase and Others v Buyende District Local Government and Attorney Gener*al HCT-03-CV-CS-135-2017.; *Uganda v Tesimana Rose Mary,* Criminal Revision No.0013 of 1999*; Uganda v Shabahuria Matia,* Criminal Revision N0.5 of 1999.

[1187] Article 1 of the UDHR states that, 'All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.'

is perpetuated by many factors. These include: inaccessible physical environment due to lack of universal designs; negative societal attitude influenced by culture and religious norms or doctrines that view PWDs as a result of a curse from the 'gods' or demonic; existence of derogatory and disempowering language in legislations that refer to especially PWMDs as 'idiot', 'imbeciles' or persons of 'unsound mind' and leading to dehumanisation and devaluing of PWMDs and negating their legal capacity; and unemployment due to low levels of education exacerbated by lack of reasonable accommodation measures that promote inclusion in employment and other economic empowerment initiatives; and in some cases, abandonment and neglect by family members due to the burdens of caregiving, to list but a few. This situation is no different in Uganda, South Africa and Kenya as has been discussed.

With specific focus on PWMDs, the situation is even more dire. The already existing stigma and discrimination PWMDs face is compounded by the inadequate financing and provision of mental health care services. As a result, institutionalisation of PWMDs in mental health facilities, prisons and asylums premised within the medical model of disability prevails globally. In some cases, PWMDs are tied to trees or isolated in a room by their own family members for fear of stigma from the community. These practices lead to a number of vices, including: to human rights violations since often times PWMDs are physically or sexually abused while in these institutions or forced to live unhygienic environment with poor living conditions; exclusion of PWMDs from their families; impeding their participation in their communities, and curtailing the realisation of their right to independent living and community inclusion now explicitly guaranteed in Article 19 of the UNCRPD and Article 14 of the ADP.

To avert the negative ramifications of institutionalisation, the global agenda has since transitioned to promoting deinstitutionalisation, and adopting strategies for provision of CMHCS.

The campaign for the provision of CMHCS is premised upon the fact that: it is less costly than institutional care; it allows for decongestion and deinstitutionalisation of mental health facilities or institutions; it enhances access to mental health care services since services are provided at the community level within reach of the PWMDs; it helps to empower the community and families with information about mental health care hence combating stigma and discrimination in the community; and most importantly it ensures that the PWMDs remains in contact with his/her family and the community. But it must be emphasized that provision of CMHCS must be buttressed with the provision of other community-based support services like counselling services, support homes, personal assistants, respite care for the families, peer-to-peer support, as well as an inclusive environment. This will enable a holistic intervention in promoting mental wellbeing and recovery, independent living and community inclusion of the PWMDs.

Grounded in the social and human rights models of disability, I advocate in this thesis that CMHCS is a necessity for Uganda to improve access to mental health care for PWMDs, decongest the mental health facilities, combat institutionalisation and promote the realisation of the right to independent living and community inclusion of PWMDs as guaranteed in Article 19 of the UNCRPD and Article 14 of the ADP. The right to independent living and community inclusion upholds the notion that PWDs must be enabled to live independently by providing them with the necessary support to be able to exercise their own free will, autonomy and choice in all aspects of life, just like their non-disabled counterparts. It does not mean that they should be left to live alone.

Laudably, Uganda recently enacted the PWD Act, 2020 and MHA, 2019. As already alluded, the new progressive laws guarantee human rights and freedoms for PWMDs and recognise the need to provide CMHCS at Primary Health Centres within reach of the PWMDs

However, the domestic legislation does not explicitly provide for the right to independent living and community inclusion as spelt out in the UNCRPD and the ADP. Hence, without a purposive interpretation of the existing laws, and government decisive political will and interventions, and complying with the UNCRPD Guidelines on Deinstitutionalisation, the celebrated right to independent living and community inclusion remains elusive in Uganda.

Furthermore, the unfortunate stories of Kabale, Kamuhanda, Mwase and the recent death of Mudoola depict the lived realities of PWMDs in Uganda and confirm the country's non-adherence to its obligation to ensure access to mental health care and also protect the rights of PWMDs to independent living and community inclusion. Inadequate funding to the mental health sector, limited staffing, ignorance of the law and non-compliance with progressive laws; centralisation of provision of mental health care at Butabika Hospital and the Regional referral hospitals are glaring challenges facing the mental health sector and inhibiting the provision of CMHCS.

Amidst the appalling reality, in cases where the PWMD is not institutionalised or abandoned, the family continues to play the critical and primary caregiving role to their members with mental disabilities. Even then, such families receive no social or economic support from the government to lessen the burdens of caregiving. For PWMDs who are abandoned and homeless, those wonder the streets until they are eventually institutionalised or meet their death.

Worse still, the provision of CMHCS and support services that are critical factors in ensuring access to mental health care and for the promotion of the right to independent living and community inclusion for PWMDs are greatly lacking largely due to underfunding and understaffing of the mental health facilities. In addition, PWMDs are also excluded from the government CBR initiative and other economic empowerment programmes that seek to promote livelihood, health, education and social inclusion of all PWDs in society.

Furthermore, although the legal recognition and protection of the rights of PWMDs is enshrined in various progressive laws and judicial decisions, it is clear that the laws and policies do not work alone. These must be supplemented within a robust policy framework with different programmatic measures that make the laws a reality to the community. Hence, Uganda must engage all her legal, and policy machinery to develop a mental health policy framework and devise an implementation plan that will actualise her legal undertakings. This thesis proposes a number of recommendations that can be adopted and effectively implemented by the government to promote CMHCS and enable PWMDs live independently and be included in their communities.

The devastating impact of the Covid-19 pandemic on the state of mental health care in Uganda is another wakeup call to the government. In addition to inadequate funding, mental health units were turned into Covid-19 treatment and quarantine centres, hence limiting admissions of PWMDs with acute or severe conditions. The lockdown measures led to increased transport costs and ultimately curtailed access to hospitals for mental health care services.[1188] The increased demand for mental health services during the Covid-19 period confirmed that an effective CMHCS model is a critical game-changer in the transformation of mental health care in Uganda.

Therefore, if Uganda wants to 'walk the talk' of its rhetorical aspirations, then it must address the challenges bedevilling the mental health sector, develop a robust policy framework, as well as implement the progressive laws and strategies identified in this thesis. This will go a long way in addressing cases of discrimination, exclusion, institutionalisation and marginalisation of PWMDs, enhancing access to mental health care services at all levels, and above all promoting the realisation of the right to independent living and community inclusion for

[1188]Lirri Evelyn, 'COVID -19 disrupts access to care for mental health'. Published on September 24th, 2021. Available on voxpopuli.ug/covid-19-d.

PWMDs.[1189] By so doing, Uganda will not only achieve its undertakings in the various legal and policy frameworks, but also secure social transformation for PWMDs, uphold the UNCRPD Guidelines on Deinstitutionalisation and the UNCRPD commitment of recognising the need to protect and promote human rights of all PWDs, including those who require more intensive support,[1190] as well as contribute towards realising the Sustainable Development Goals (SDG) pledge of 'leaving no one behind, while endeavouring to reach the furthest behind first.'[1191]

[1189] MDAC and MHU, 'They don't consider me as a person', at 47.
[1190] UNCRPD Preamble, para (j).
[1191] United Nations, 'Transforming our World: The 2030 Agenda for Sustainable Development: A/ RES/70/1', para 4, at 7.

Traditionally over the last decades the standard approach of many countries has been to provide mental health services in large specialized hospitals often associated with poor care outcomes and human rights violations. An increasing number of countries are making efforts to profoundly reform their hospitals to ensure that a sustainable process of deinstitutionalization and a human rights-based approach can be achieved. Any responsible process of deinstitutionalization needs to be accompanied by a set of comprehensive reforms for the entire mental health care system, including the development of alternative community-based services, as well as a shift in the workforce mindset towards person-centred care, rights-based support and the recovery approach. (WHO: Guidance on Community mental health services', at 174)

Uganda should not lag behind the ongoing transition.

ANNEXTURE 1

LIST OF INMATES ON MINISTER'S ORDER AT UGANDA LUZIRA UPPER PRISON AS OF 07/05/2021

S/NO.	NAMES	CASE NO.	OFFENCE	CATEGORY	PERIOD SPENT IN PRISON	REMARKS AND DATE OF ORDER	STATE OF HEALTH
	Ojok Omony Julius	CSC. 47/02	Defilement	Remand	**20 years and 4 months**	Placed under Minister's order during the trial on 19/03/07 due to insanity. **Age on arrest: 20 years** **Current age: 40 years**	Schizophenia
	Byamukama Alfred	CSC 42/98	Murder	Remand	**22 years and 8 months**	Placed under Minister's order during the trial on **15/11/2000** due to insanity. **Age on arrest: 25 years** **Current age: 47 years**	Schizophenia
	Okot Micheal	CSC. 264/07	Murder	**Convicted**	**12 years and 11 months**	Placed on Minister's order during the trial on **07/08/2009** due to insanity. **Age on arrest: 30 years**	Schizophenia

						Current age: 43 years	
	Gumisiriza John	Csc.265/10	Murder	Remand	**9 years and 11 months**	Placed on Minister's order during the trial on 4th March 2013 due to insanity. **Age on arrest: 24 Yrs.** **Current age: 33 years**	Schizophenia
	Byaruhanga Robert	Csc.84/09	Murder	Remand	**9 years and 8 months**	Placed on Minister's order during the trial on **28/10/2010** due to Insanity. **Age on arrest: 29 years** **Current age: 38 years**	Schizophenia
	Kibirigye Habibu	Csc.140/06	Murder	Convict	**10 years and 7 months**	Placed under Minister's order during the Appeal on **08/12/14** due to insanity. **Age on arrest: 22 years** **Current age: 32 years**	Schizophenia

	Obulejo Gift Moses	Csc.029/13	Murder	Convict	**5 years and 7 months**	Placed under Minister's order during the trial on **22/09/14**. **Age on arrest: 24 years** **Current Age: 29 years**	Not mentioned on warrant
	Muhumuza Wallen	Csc.222/06	Murder	Remand	**13 years and 6 months**	Placed under Minister's order during the trial on **08/01/15** due to insanity. **Age on arrest: 28 years** **Current age: 41 years**	Schizophenia
	Sekajja Joseph	Csc.194/07	Agg Defilement	Remand	**12 years and 11 months**	Placed on Minister's order during the trial on 24th August 2010 due to Insanity. **Age on arrest: 25 years** **Current age: 37 years**	Schizophenia
	Kalute Ismail	Csc.066/09	Murder	Remand	**10 years and 2 months**	Placed on Minister's order during the trial on 27/05/2013 due to Insanity.	Schizophenia

						Age on Arrest: 27 years **Current age: 37 years**	
	Mukasa Ibraim Muwonge	Csc.117/11	Agg Defilement	Remand	**8 years and 7 months**	Placed on Minister's Order during the trial on **22/09/2011** due to Insanity. **Age on arrest: 29 years** **Current age: 30 years**	Schizophenia
	Omeja Chrisesto alias Omejaluo	CSC. 167/04	Murder	Remand	**16 years**	Placed on Minister's order during the trial on **04/11/2009** due to in sanity. **Age on arrest: 44 years** **Current age: 60 years**	Schizophenia
	Bambala Joseph	CSC. 0184/05	Defilement	Remand	**14 years and 2 months**	Placed under minister's order during the trial on **05/05/08** due to insanity. **Age on arrest: 15 years** **Current Age: 29 years**	Schizophenia

	Byamukama John Yowana	CSC 66/06	Defilement	Remand	**14 years and 10 months**	Placed under Minister's order during the trial on **22/10/2007** due to insanity. **Age on arrest: 35 years** **Current age: 49 years**	Schizophenia
	Mpanga James	Csc.253/13	Murder	Convict	**17 years and 7 months**	Placed under Minister's order during mitigation on 05/12/2013 due to insanity. **Age on arrest: 22 years** **Current age: 39 years**	Schizophenia
	Isiiko David	Csc.139/03	Murder	Convict	**16 years and 7 months**	Placed under Minister's order during mitigation on 22/11/2013 due to insanity. **Age on arrest: 20 years** **Current age: 36 years**	Schizophenia
	Tirwomwe James	Appeal 668/14	Murder	Remand	**06 years & 5 months**	Placed under minister's order during the	Not mentioned on warrant

						Appeal hearing: 02**/10/18**. **Age on arrest 39 years** **Current age: 45 years**	

ANNEXTURE 2:

PUBLISHED STORY OF KHOMUHANDI

ANNEXTURE 3:

TABLE SUMMARISING THE COMPARATIVE ANALYSIS BETWEEN UGANDA, SOUTH AFRICA AND KENYA

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