Community based mental health care and services in South Africa: A human rights approach

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by

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Dedication

To my family, I salute each and every one of you. We are strong together!

To persons with lived experience, you inspire me to make the world a better place!

Acronyms/Abbreviations

ACHPR	African Charter for Human and Peoples Rights
CBO	Community Based Organisations
CBR	Community Based Rehabilitation
CRPD	Convention on the Rights of Persons with Disabilities
HIV/Aids	Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome
INDS	Integrated National Disability Strategy
LMIC	Low Middle Income Country
LOI	List of Issues
MHCA	Mental Health Care Act (the Act)
MHCU	Mental Health Care User
MHPF	Mental Health Policy Framework
NGO	Non- Governmental Organisation
NPO	Non-Profit Organisation
PHC	Primary Health Care
SIAS	National Strategy on Screening, Identification, Assessment and Support
UCT	University of Cape Town
UDHR	Universal Declaration of Human Rights
USPK	Users and Survivors of Psychiatry Kenya
WHO	World Health Organisation

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Chapter One: Introduction

1.1 Background

According to the World Health Organisation (WHO) health systems everywhere, including in South Africa, do not prioritise mental health and community mental health care is underfunded within mental health budgets.[1] Following a human rights approach in mental health policy and legislation should guarantee access to mental health care in the community for persons with psychosocial and intellectual disabilities.[2] Community based mental health care is care that is provided within the community where people live, work and study and most importantly it is care that is outside of institutions and hospital settings.[3] Community based mental health care is a 'network of interconnected services,'[4] which include medical mental health and community services within the general public health care system, and social care services provided in non-health settings which provide access to much needed social services.[5]

In South Africa, community based mental health social care services are provided by non-governmental, community based organisations (CBOs) that are allocated Non Profit Organisational (NPO) status and registration by the Department of Social Development.[6] CBOs fall outside of the health system (non-health settings) and provide human rights focused social services to persons with psychosocial and intellectual disabilities and their families to ensure community participation and inclusion.[7] The services provided by CBOs complement the health services provided by provincial government departments (health). Furthermore, CBOs provide services to communities where government is unable to do so.[8] These organisations are also represented by persons with disabilities who are involved in and guide the planning of programmes and services.[9] Policy and legislation makes provision for inter-sectoral collaboration between government departments that are responsible for health care in South

[1] 'World mental health report: transforming mental health for all' *Geneva: World Health Organization* (2022) 17.
[2] DL Marais & I Peterson 'Health system governance to support integrated mental health care in South Africa: challenges and opportunities' (2015) 9:14 *International Journal of Mental Health Systems* 2.
[3] National Mental Health Policy Framework and Strategic Action Plan 2013-2020 (MHPF) 6.
[4] 'World mental health report: transforming mental health for all' (n 1) 21.
[5] 'World mental health report: transforming mental health for all' (n 1) 21.
[6] A Parekh & I Petersen 'The role of mental health NGOs in South Africa: before; during and after political transition' (1997) *Journal of Psychology in Africa* 4.
[7] Parekh & Peterson (n 6) 9.
[8] Parekh & Peterson (n 6) 9.
[9] 'World mental health report: transforming mental health for all' (n 1) 21.

Africa to ensure comprehensive service provision.[10] The health sector has been widely criticised for its over-reliance on the medical approach to mental health within tertiary institutions.[11] Despite the adoption of human rights focused mental health legislation and policies, South Africa continues to spend most of the mental health budget on institutionalised care with very little funding directed towards community based mental health services.[12] CBOs, which are partially funded by the state, provide social care services so that persons with psychosocial and intellectual disabilities are fully integrated into the community when they are discharged from institutions.[13] Historically, mental health CBOs were formed by community members who identified social service gaps in communities, such as, the need for residential and day care facilities for persons with psychosocial and intellectual disabilities.[14] During the Apartheid era persons with disabilities were institutionalised as the intention was to protect society from their fear of persons with disabilities and shifted attitudes towards feelings of pity for persons with disabilities.[15] Nevertheless, CBOs were instrumental in the fight for democracy, ensuring that persons with disabilities were organised and empowered to also have a voice in the new democracy. CBOs, including mental health CBOs are now regulated by the Department of Social Development and are acknowledged as important social partners who provide mental health services in the community.

1.1.1Terminology

It is necessary to understand the terminology used in the mental health environment and how it is applied within a rights based approach towards mental health care. The terminology also provides a better understanding of the mental health programmes and services provided by CBOs.

- **Community-Based Rehabilitation and Habilitation (CBR)** is a programme that provides opportunities for persons with disabilities to learn new skills or master skills lost due to changes or barriers in the environment such that they can reach optimal levels of independent functioning.[16] The programme requires the full cooperation of all parties that can offer support to persons with disabilities and can include family

[10] Mental Health Care Act 17 of 2002 (MHCA) 19.
[11] Marais & Peterson (n 2) 8.
[12] Marais & Peterson (n 2) 10.
[13] Marais & Peterson (n 2) 10.
[14] Parekh & Peterson (n 6) 9.
[15] Integrated National Disability Strategy (INDS) White Paper November 1997.
[16] 'Community based rehabilitation (CBR) Africa Network' https://afri-can.org/what-is-cbr/ (accessed 5 June 2022).

members, neighbours, and religious leaders, as well as government departments such as labour, health, education and social development.[17]

- **Mental Health Care User (MHCU)** is anyone receiving mental health services or receiving treatment at a health clinic to improve their mental wellbeing.[18]
- **Mental Disability** refers to those who have a mental health condition or intellectual impairment over a long period of time.[19]
- **Non-governmental organisations (NGOs)** are voluntary, private or organisations that provide free services to improve the lives of disadvantaged people.[20] This term is used interchangeably with CBOs although CBOs is the preferred term for NGOs that provide direct social services to local communities.
- **Psychosocial disability** refers to the disabling environment experienced by persons with mental health conditions. The external environment creates barriers in the interaction with the impairment that prevent persons with disabilities from participating in society.[21] This is the terminology that is used by international human rights mechanisms.
- **Intellectual disability** refers to impairments in intellectual functioning which can range from being able to function independently with little support to requiring full support in daily activities.[22]

1.1.2 A human rights focus for mental health in South Africa

South Africa has a colonial past with segregation based on race and ethnicity.[23] The apartheid government's harsh treatment of persons with psychosocial and intellectual disabilities, characterised by severe sedation and institutionalisation in inhumane conditions further fuelled the stigma and discrimination towards mental health.[24] In 1994, the newly elected democratic government of South Africa gave much hope for freedom and human

[17] 'Community based rehabilitation (CBR) Africa Network' (n 17).
[18] MHPF (n3) 7.
[19] SA Federation for Mental Health https://www.safmh.org/(accessed 2 August 2021).
[20] AC Vakil 'Confronting the classification problem: Toward a taxonomy of NGOs' (1997) *World Development*.
[21] 'World mental health report: transforming mental health for all' (n 1) 8.
[22] American Association on Intellectual and developmental disabilities (AAIDD) https://www.aaidd.org/intellectual-disability/definition#:~:text=Intellectual%20disability%20is%20a%20condition,before%20the%20age%20of%2022 (accessed 26 August 2022).
[23] WPRPD (n 15)17.
[24] MHPF (n 3) 13.

dignity for persons with psychosocial and intellectual disabilities.[25] The inclusion of the Bill of Rights[26] in the Constitution of the Republic of South Africa (the Constitution),[27] brought about hope to all for a fair and equal society irrespective of race, gender, age, ethnicity and disability.[28] Section 27 of the Constitution includes the right to health care, food, water and social security reflecting an obligation of the state to ensure that the social aspects of health care are included in the attainment of health, which comprises physical and mental health.[29]

The White Paper on the Transformation of the Health System in South Africa supported deinstitutionalisation and a commitment towards community based mental health care to ensure that services were accessible and available near to where people live and work.[30] Prior to democracy mental health services were centred in urban and tertiary settings, which made it impossible for the majority of South Africans, especially people in rural communities, to access services.[31] The Mental Health Care Act 17 of 2002 (the Act),[32] regulated the integration of mental health from tertiary institutions into the Primary Health Care (PHC) system so that all communities would have access to mental health and physical health care at the same place.[33] This integration was to reduce stigma and discrimination of mental health in communities.[34] It was also envisaged that CBOs would provide mental health education programmes in addition to planning and providing mental health social services.[35]

The Act, received much praise for its human rights approach, taking into consideration the United Nations Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (MI Principles).[36] Issues of rehabilitation and reintegration, community based care and services, as well as the development of district hospital infrastructure and Mental Health Review Boards were specifically included and emphasised to ensure that persons with psychosocial and intellectual disabilities had

[25] JK Burns 'The mental health gap in South Africa - A human rights issue' (2011) 6 *The Equal Rights Review* 99 at 100.
[26] Chapter 2 Constitution (n 28) 5.
[27] Constitution of the Republic of South Africa 1996 as adopted on 8 May 1996 and amended on 11 October 1996 by the Constitutional Assembly (Constitution).
[28] Constitution (n 28).
[29] Constitution (n 28) 11.
[30] White Paper on the Transformation of the Health System in South Africa 1997.
[31] N Mkhize & MJ Kometsi 'Community Access to Mental Health Services: Lessons and Recommendations' (2008) 1 *South African Health Review* 103 at 104.
[32] MHCA (n10) 2.
[33] MHCA (n 10) 14.
[34] MHCA (n 10) 14.
[35] MHCA (n 10) 14.
[36] United Nations Principles for the protection of persons with mental illness and the improvement of mental health care adopted on 17 December 1991 by General Assembly resolution 46/119.

jurisdiction to claim their rights.[37] This ensured that persons with psychosocial and intellectual disabilities were not mere beneficiaries of mental health medical treatment only, but equal rights holders who can participate and contribute towards the community in which they live on an equal basis with others.[38]

When South Africa ratified the Convention on the Rights of Persons with Disabilities (CRPD)[39] in 2007, it showed commitment to implementing and ensuring a social developmental and human rights focus on mental health.[40] The State's responsibility to consult with and include civil society organisations (CBOs) of persons with disabilities, ensures that persons with disabilities participate and contribute towards decision making processes.[41] Article 19 of the CRPD on the right to live independently and be included in the community promotes the opportunity of choice available to persons with disabilities in terms of how, where and with whom they choose to live within the community.[42] The CRPD has introduced significant changes to the accessibility and availability of services for persons with psychosocial and intellectual disabilities.

The MHPF was gazetted following a lengthy national and local consultation with all parties including persons with psychosocial and intellectual disabilities.[43] The National Department of Health made a bold commitment to move away from a purely medical focus on mental health care taking into consideration the social barriers to care within a human rights approach, to ensure that quality mental health services are accessible, equitable, comprehensive and are integrated at all levels of the health system.[44] In doing so, the focus of mental health programs and services is no longer on fixing the impairment of individuals but rather on addressing the social determinants of mental health like stigma and discrimination, poverty and promotion of mental health.[45] The MHPF aligned to the CRPD, also recognised the role of CBOs in providing much needed social integration programmes and made commitments to ensuring that funding will be directed towards the capacitation of CBOs providing mental health services.[46] The MHPF lapsed in 2020 and is yet to be reviewed.

[37] Burns (n 26)100.
[38] Burns (n 26) 100.
[39] Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the General Assembly of the United Nations on 13 December 2006 with UNGA Res 61/106 and entered into force on 3 May 2008.
[40] Burns (n 26) 106.
[41] Burns (n 26) 108.
[42] CRPD Article 19 (n 41).
[43] MHPF (n 3) 9.
[44] MHPF (n 3) 22.
[45] MHPF (n 3) 19.
[46] MHPF (n 3) 20.

Nevertheless, South Africa made great progress in developing human rights focused mental health legislation and policy for persons with psychosocial and intellectual disabilities to access care in the community and acknowledged the important role of CBOs to provide community based mental health services.

1.2 Problem Statement

Despite having standalone mental health legislation and policy, persons with psychosocial and intellectual disabilities do not have access to community based mental health care and services.[47] The PHC system is still following a highly medicalised approach to mental health care, which is problematic as attention should be on the provision of social care services to enjoy all other fundamental rights and freedoms on an equal basis with others.[48] According to the WHO one of the benefits of community based mental health services is that 'community services can reach people where they live and work, thereby increasing access to mental health-related activities and interventions, as well as to other social support services.'[49] It is therefore crucial to analyse the important role CBOs play in increasing access to community based mental health services for all citizens, including persons with psychosocial and intellectual disabilities.[50] There is very little research undertaken in South Africa to measure the progress made to develop community based mental health services to provide wide scale psychosocial and rehabilitation support, and mental health promotion programmes to the majority of South Africans as prescribed in the CRPD.[51]

1.3 Research question

The main research question is how can access to community based mental health services provided by CBOs in South Africa, be improved? In order to address the main question, several sub-questions will be addressed:

a) What is the conceptual framework that can be used to analyse community based mental health services?
b) What are some of the barriers to accessing mental health services provided by CBOs?

[47] Mkhize & Kometsi (n 31)106.
[48] Covenant on Economic, Social and Cultural Rights (CESCR) was adopted by the General Assembly of the United Nations on 16 December 1966 with UNGA Res 2200A (XXI) and entered into force on 3 January 1976.
[49] 'mhGAP community toolkit: field test version' *Geneva: World Health Organization* (2019).
[50] SA Human Rights Commission SAHRC) 'National investigative hearing into the status of mental health care in South Africa' 47.
[51] Mkhize & Kometsi (n 32) 106.

c) What interventions are available to address barriers to accessing CBO mental health services?

d) What measures can South Africa implement to address barriers to accessing CBO mental health care?

1.4 Methodology

The methodology used is a desk top review of primary sources including international and regional human rights framework as well as national legislation that make provision for persons with intellectual and psychosocial disabilities to have access to community based mental health services. Furthermore, researcher will also examine secondary sources including journal articles, reports and books that analyse the extent to which national legislation and policy complies with international and regional human rights obligations.

1.5 Limitations of the Study

This study is limited in that there was insufficient time in the programme to conduct empirical research. Empirical research would have produced rich data that would have generated significant information on the needs and current experiences of persons with psychosocial and intellectual disabilities in accessing community based mental health services.

1.6 Literature Review

Globally there are over 970 million people living with a mental health condition.[52] 'Mental health conditions can have a significant impact not only on the health and well-being of those affected but also on their families, friends and the communities they live in.'[53] Persons with psychosocial and intellectual disabilities are severely affected by stigma in society, reporting experiences of 'discrimination, violations of their rights and social exclusion by members of the general public, social welfare or educational systems, and even at times the health-care system.'[54] The stigma and discrimination by society towards persons with mental health conditions creates barriers that prevent them from accessing basic human rights like employment, housing, education and health care services.[55]

The WHO recognises mental health as more than an absence of illness and promotes the inclusion and community participation of persons with psychosocial and intellectual

[52] Institute for Health Metrics and Evaluation (IHME) 'Findings from the Global Burden of Disease Study 2017'.
[53] World mental health report: transforming mental health for all' (n 1) 16.
[54] 'mhGAP community toolkit: field test version' (n 50) 3.
[55] 'mhGAP community toolkit: field test version' (n 50) 3.

disabilities.[56] Furthermore, there is worldwide support for mental health to be addressed from a human rights based approach versus the medical model of care, so as to combat the various external barriers of stigma and discrimination, lack of investment in mental health and insufficient promotion strategies to reduce the barriers which prevent access to community based mental health care.[57] There is a huge gap in accessing mental health services for the majority of the population with current data showing that only a third of those in need of care are actually receiving care.[58] It is further argued that in low and middle income countries (LMIC) there is a lack of financial and human resources and that these resources are not adequately utilised to provide mental health services appropriately.[59] Community based mental health care is described as a 'network of interconnected services,' which include among others 'community mental health organisations that deliver mental health care in non-health settings and support access to key social services.'[60]

Since 1994, South Africa has made a concerted effort to uphold the basic human rights of all citizens.[61] However, persons with psychosocial and intellectual disabilities still face barriers which prevent their full inclusion and participation in the community.[62] Some of the advantages of community based mental health services is that it ensures that persons with psychosocial and intellectual disabilities receive care and services outside a medicalised environment and also that services are close to communities making services affordable and accessible, reaching larger populations.[63] Access to quality, rights based mental health care in the community is impacted negatively as resources for mental health services are still mostly directed towards institutionalised care in tertiary hospitals instead of community based mental health services which have better reach to poor communities showing that there is still bias towards the medical model of disability.[64]

CBOs in South Africa form part of the community based mental health system but lie outside of the Primary Health Care (PHC) system, which is mandated by the National

[56] 'World mental health report: transforming mental health for all' (n 1) 14.
[57] 'World mental health report: transforming mental health for all' (n 1) 14.
[58] 'mhGAP community toolkit: field test version' (n 50) 3.
[59] 'mhGAP community toolkit: field test version' (n 50) 3.
[60] 'World mental health report: transforming mental health for all' (n 1) 21.
[61] Burns (n 26) 100.
[62] Convention on the Rights of Persons with Disabilities 'Concluding observations on the initial report of South Africa' (CRPD Concluding Observations) UN Doc CRPD/C/ZAF/CO/1 adopted on 7 September 2018.
[63] C Lund & AJ Flisher 'A model for community mental health services in South Africa' *Tropical Medicine & International Health* (2009) 402 at 404.
[64] 'World mental health report: transforming mental health for all' (n 1) 17.

Department of Health.[65] CBOs provide much needed psychosocial rehabilitation services and link persons with psychosocial and intellectual disabilities and their families to education, employment, housing, food, water and electricity as well as support services.[66] Support services like social work are critical in facilitating access for persons with disabilities to other resources near to where they live and work.[67]

1.7 Significance of the research

While there has been some research about barriers that prevent persons with psychosocial and intellectual disabilities from accessing mental health care in South Africa, there has been very little research that focuses on the critical role played by CBOs to ensure a human rights approach to mental health care in South Africa. Therefore, this research will contribute to the discourse by examining the barriers that prevent access to mental health services provided by CBOs for the majority of citizens. The research will also highlight good practice models implemented in other WHO member countries that can be considered for implementation in South Africa.

1.8 Chapter outlines

This dissertation is divided into four chapters as follows:

Chapter One will provide a historical background of mental health legislation in South Africa and provide context as to why the human rights based approach to mental health care is significant and what commitments have been made to citizens since democracy.

Chapter Two will explore three models of disability to identify a conceptual framework that can be used to analyse the critical role of community based mental health services in South Africa.

Chapter Three will examine the barriers to accessing community based mental health services for persons with psychosocial and intellectual disabilities.

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[65] I Peterson, A Bhana, V Campbell-Hall, S Mjadu, C Lund, S Kleintjies, V Hosegood & AJ Flisher 'Planning for district mental health services in South Africa: a situational analysis of a rural district site' (2009) *Health Policy and Planning* 140 at 146.

[66] 'Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health' A/HRC/35/21 1 at 4.

[67] A Janse van Rensburg, I Peterson, E Wouters, M Engelbrecht, G Kigozi, P Fourie, D van Rensburg & P Bracke 'State and non-state mental health service collaboration in a South African district: a mixed methods study' *Health policy and planning* (2018) 516 at 522.

Chapter Four will explore solutions to addressing the barriers identified and highlighting good practice examples from other countries, concluding with recommendations of measures for implementation in South Africa.

Chapter Two: A conceptual framework for analysing community based mental health services

2.1 Introduction

There are various models or approaches to understanding disability.[68] It is important to understand disability as a concept and how the various models of disability influence the way governments respond to the needs of persons with disabilities and further how society views persons with disabilities. This chapter will examine and analyse three models of disability, namely the medical model, social model and the human rights model or approach to disability and their impact on persons with intellectual and psychosocial disabilities. It is argued that the manner in which disability is perceived has an influence on one's response to persons with disabilities.[69]

The three main models of disability will be examined in relation to mental health and how these models influence the treatment and social care services provided to persons with intellectual and psychosocial disabilities. The discussion below will start with the medical model, which according to the literature reviewed was the first of the three models of disability to be identified, specifically during the industrial revolution.[70] From there, the social model of disability, which emerged in the 1980s with the rise of the disability rights movement will be examined. Finally, the human rights model or approach to disability will be analysed.

2.2 Medical model of disability

The medical model of disability has been described as an approach that views disability as an individual problem where there is a loss of function or body part and something that needs to be fixed.[71] The focus is on the physical impairment where the body parts are absent or do not function properly and therefore needs an adjustment through the use of devices like a wheelchair, prosthesis, a cane for the blind and medication for mental illness.[72] The problem is identified within the individual who is dependent on the health system to address the deviations in bodily form and function such that the person can then conform to norms of society.[73] The

[68] M Retief & R Letšosa 'Models of disability: A brief overview' (2018) *Theological Studies* 1 at 3.
[69] Retief & Letšosa (n 68) 3.
[70] Retief & Letšosa (n 68) 3.
[71] AJ Hogan 'Social and medical model of disability and mental health: evolution and renewal' (2019) Canadian medical association journal 16 at 16.
[72] Hogan (n71)16.
[73] G Quinn & T Degener 'Human rights and disability: The current use and future potential of United Nations human rights instruments in the context of disability' (2002) 10.

medical model sees the impairment as the object and ignores the person as a whole.[74] The medical model was first described in psychiatric literature by Thomas Szasz as an 'oppressive and stigmatising approach to disability and mental health.'[75] At the time the medical profession was criticised for its narrow focus on disability as a medical issue only and that there was a need to start exploring alternative approaches to treating disabilities by looking at not only addressing the biology of disability but to go beyond medicine and consider societal influences on persons with disabilities and mental health.[76] This approach was not well received by the medical fraternity as it threatened the role of medicine in addressing disability and mental health.[77] George Engel, a psychiatrist in the 1970s provided a slightly altered view by suggesting that since mental illness is a disease and that biological causes of disability cannot be ignored, disability therefore must be addressed from a 'biopsychosocial' approach thereby defending the role of medicine in addressing disability and mental health.[78] Critiques from the field of psychology like George Albee spoke out against purely psychiatric interventions to mental health and disability as 'overly pathologising disability in general.'[79] The medical model of disability singled out people with disabilities as different from other human beings resulting in their isolation from society and reducing them to objects of medical investigation. The care that was provided by social care services within institutional settings further reinforced this separation from society while imposing societal decisions of what, where and how persons with disabilities should be treated.[80]

2.2.1 Medical model in the apartheid era

Racial segregation under the apartheid regime reinforced the medical approach to disability leading to further discrimination and isolation of persons with disabilities.[81] The health system provided medical treatments only within the hospitals and civil society (CBOs) were tasked to provide social care services to persons with disabilities in the community at day care and residential type facilities.[82] Social welfare services were limited to the issuing of grants and rehabilitation services to 'fix' the impairments was the responsibility of the Department of

[74] WPRPD (n 15) 17.
[75] TS Szasz 'Some observations on the relationship between psychiatry and the law' (1956) *American Medical Association Archives Neurology & Psychiatry.*
[76] Quinn & Degener (n 73) 10.
[77] Hogan (n 71) 17.
[78] Hogan (n 71) 17.
[79] G Albee 'To thine own self be true' (1975) *American Psychology.*
[80] WPRPD (n 15) 18.
[81] WPRPD (n 15)18.
[82] INDS (n 16) 6.

Health.[83] This resulted in excluding persons with disabilities, mainly black people with disabilities from the mainstream society, denying any access to education, employment and housing.[84]

2.2.2 Impact of the medical model on persons with mental disabilities in South Africa

Within a racialised and segregated society, certain sectors of the population experienced greater exclusion than others.[85] Within the disabled communities vulnerable sectors included: Black women, children with disabilities (especially black children), persons with severe intellectual or mental disabilities, youth and the elderly as well as those living in rural communities.[86] The list of those affected could go on, however, for the purpose of this paper the focus will be on persons with intellectual and psychosocial disabilities.

Many community based organisations were formed by people from the community themselves (like parents or siblings of persons with disabilities) to provide basic social services of care for their own family members who were diagnosed with disabilities.[87] Persons with intellectual disabilities, especially children, were sent to special schools that provided 'care' within an institutionalised setting.[88] Investigations into many of these institutions revealed gross human rights violations as these institutions were poorly funded and there was a lack of monitoring of these institutions.[89]

2.3 Social model of disability

The social model of disability turned the focus onto societal barriers, which restrict the full integration of persons with disabilities into society.[90] Societal stigma towards persons with disabilities is as a result of not understanding and accepting the broader needs and capabilities of persons with disabilities.[91] Dunn explains that this lack of understanding can lead to stereotyping persons with disabilities as being distinctly different from the rest of society.[92] Society seems to have a preconceived perception of what is 'normal' and tend to categorise

[83] WPRPD (n 15)18.
[84] INDS (n 16) 6.
[85] INDS (n 16) 8.
[86] INDS (n 16) 6.
[87] INDS (n16) 9.
[88] INDS (n 16) 9.
[89] INDS (n16) 9.
[90] C Barnes, G Mercer & T Shakespeare 'The social model of disability' in A Giddens & P Sutton (eds) *Sociology: Introductory readings* (2010)161 at 166.
[91] https://www.afdo.org.au/social-model-of-disability/ (accessed 9 June 2022).
[92] D Dunn *the social psychology of disability* (2014) 42.

people according to their physical appearance or behaviour. The social model makes it distinctly clear that it is the external barriers, attitudes and actions of society in interaction with the impairment that causes the disability and not the environmental barriers alone.[93] For persons with psychosocial and intellectual disabilities, stigma and attitudinal barriers mostly hinder their full participation in society and it is therefore proposed that CBOs use social interventions like awareness and information sharing to change societal attitudes to reduce stigma in mental health.[94]

2.4 How do the medical and social models of disability compare to the human rights approach to disability

The social model of disability looks at disability as an external, socially constructed phenomenon which creates barriers to access and participation in society for persons with disabilities.[95] The human rights model of disability identifies the person with a disability as a human being with inherent dignity and capacity to make decisions about themselves by themselves with the necessary support available, if required.[96] Unlike the medical model, the social and human rights models are similar in that disability is not seen as a problem existing internally within the person but rather that the problems are in the external environment and with the society at large in their interaction with the impairments.[97] According to Quinn and Degener, the human rights model builds on the social model, and instead of providing another concept of disability, it explores opportunities for developing policies and legislation, acknowledging persons with disabilities as rights holders as opposed to being the subject of societal oppression.[98] The significance of the human rights approach is that persons with disabilities are recognised as equal citizens with civil, political, socio-economic and cultural rights.[99]

2.5 Conclusion

An understanding of the various models of disabilities provides valuable context to how disability is viewed by society in general, how persons with disabilities have been treated by

[93] A Lawson and AE Beckett 'the social and human rights models of disability: towards a complementarity thesis' (2021) 348 at 356.
[94] Lawson and Beckett (n 93) 349
[95] Lawson & Beckett (n 93) 356.
[96] G Quinn & T Degener 'The moral authority for change: human rights values and the world wide process of disability reform' (2002) *Human Rights and Disability*.
[97] Quinn & Degener (n 95).
[98] Quinn & Degener (n 95).
[99] T Degener 'A new human rights model of disability' in VD Fina et al (eds) (2017) *The United Nations convention on the rights of persons with disabilities.*

society and the societal impact on the lives of persons with disabilities from a human rights perspective to disability. The medical model of disability is fragmented and limited and does not address the full needs of persons with disabilities as the intention is to fix the impairment by administering medication, issuing assistive devices to ensure that persons with disabilities conform to the norm.[100] The social model of disability provides valuable explanations for how persons with disabilities' lives have been impacted by a biased and stigmatised society, and the human rights approach provides opportunities to remedy societal impact through policy implementation.[101] Lawson opines that the social model has contributed immensely to the CRPD, more specifically noting that the rights of persons with disabilities are not granted on the basis of the disability or impairment itself but rather because persons with disabilities enjoy the same fundamental rights inherent in all human beings.[102]

It is against this backdrop that the social model of disability will be used to further examine the barriers to accessing community based mental health care and services provided by CBOs in South Africa within the human rights framework. Since the social model focuses on the environment and society as instrumental in creating barriers which prevent or restrict persons with disabilities from accessing services thereby violating their rights to participate in society,[103] it is also then appropriate to use the social model to justify social interventions that can be used to address the barriers identified from a human rights perspective. Community support services offered by CBOs provide persons with psychosocial and intellectual disabilities with holistic mental health services they require, looking at the individual as a whole and not by their impairment, respecting them as rights holders, with a right to health and the right to live and participate in the community. The social and human rights models of disability ca be effective in ensuring that persons with psychosocial and intellectual disabilities gain access to employment, housing, education and health care by advocating for the human rights of persons with disabilities and shifting attitudes of society in the process.

[100] Degener (n 99).
[101] Degener (n 95).
[102] Lawson & Beckett (n 93).
[103] https://www.afdo.org.au/social-model-of-disability/ (accessed 15 August 2022).

Chapter Three: Barriers to accessing community based mental health services for persons with psychosocial and intellectual disabilities

3.1 Introduction

It has been established that the community based mental health system include CBOs that deliver mental health services outside of the health care system and play a significant role in integrating persons with psychosocial and intellectual disabilities into the community.[104] The focus of CBOs is on the provision of social care services within a human rights approach. Internationally, disability rights movements had been instrumental in calling for a disability specific mechanism and have made significant contributions towards the CRPD. The Protocol to the African Charter on Human and Peoples Rights on the Rights of Persons with Disabilities (African Disability Rights Protocol)[105] adopted by the African Union on 30 January 2018 has not yet been entered into force, as it requires at least fifteen African States to sign and ratify the protocol.[106] The African Disability Protocol addresses issues that are specific to the African continent that are not addressed in the CRPD like poverty, HIV/ Aids, harmful killings of persons with albinism and dual discrimination of woman and children with disabilities.[107] The African Disability Protocol like the CRPD recognises the role of CBOs as critical enablers in ensuring access to community based mental health care.

CBOs play a significant role towards ensuring that persons with psychosocial and intellectual disabilities have access to psychosocial rehabilitation and support services and access to other basic rights like education, employment, housing, food, water and electricity.[108] These services are provided in communities close to where people live and work making these services accessible, affordable (often at no cost), available and of high quality within a human rights framework.[109] Government departments like the Department of Health and the Department of Social Development have also acknowledged that partnerships with CBOs have been beneficial in ensuring that basic mental health social services reach the broader population.[110] However, persons with psychosocial and intellectual disabilities experience

[104] 'mhGAP community toolkit: field test version' (n 50) 4.
[105] Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (African Disability Protocol) adopted on 29 November 2018.
[106] https://www.chr.up.ac.za/ratifyadrp-about (accessed 20 November 2021).
[107] SAD Kamga 'A call for a protocol to the African Charter on Human and Peoples' rights on the rights of persons with disabilities in Africa' (2013) African journal if international and comparative law 219 at 227.
[108] 'Report of the Special Rapporteur 2017' (n 66).
[109] 'Report of the Special Rapporteur 2017' (n 66).
[110] SAHRC (n 51).

significant barriers to accessing community based mental health services provided by CBOs in South Africa. This chapter will identify and analyse these barriers against the social model of disability taking into consideration the rights of persons with psychosocial and intellectual disabilities.

3.2 Stigma and Discrimination

Erwin Goffman in his book *Stigma: Notes on the management of spoiled identity*, explains stigma as a concept experienced by people who are different from the 'norm.'[111] People are stigmatised because they are different in either body formation or mental capacity and these differences are perceived to be undesirable by the general population.[112] The focus is rather on the differences or deviation of persons with disabilities' bodies and minds, which results in stigma and isolation.[113] The stigma assigned to persons with disabilities leads to discriminatory practices in all spheres of life including education, employment, relationships, and even recreational and sporting activities. Marguerite Schneider explains 'disability as an experience that arises out of the interaction between a person with a health condition and the context in which they live.'[114] Schneider`s explanation of the environment as including the 'physical, attitudinal and social' aspects are aligned to Goffman's definition of stigma and goes further to provide a comprehensive overview of the external issues that affect the degree to which persons with disabilities can participate or experience barriers in society.[115] Schneider also touches on how the external environment affects legislation and policy, specifically how laws are constructed to deny persons with disabilities, more especially persons with intellectual and psychosocial disabilities from being involved in decisions that affect them and their participation in society.[116] According to Ditchman and others, persons with mental disabilities experience extreme forms of exclusion in the form of stigma when it comes to employment, health and housing.[117] Sartorius notes that the stigma in mental health is associated with the negative attitude that people and society have towards persons who behave differently, which is linked to illness and psychiatry.[118] From the above it is apparent that stigma is a socially developed concept and that stigma and discrimination exists in the

[111] E Goffman 'Stigma: notes on the management of spoiled identity' *New York Touchstone* (2014).
[112] Goffman (n 109).
[113] Goffman (n 109).
[114] M Schneider 'Disability and the environment' (2006) *Disability and Social Change: A South African Agenda.*
[115] Schneider (n 112).
[116] Schneider (n 112).
[117] Ditchman et al 'Stigma and intellectual disability: potential application of mental illness research' (2013) 206 *Rehabilitation Psychology* 58.
[118] N Sartorius 'Stigma and mental health' (2007) 810 *the lancet* 370.

external environment in relation to persons with psychosocial and intellectual disability. To have a better understanding of how stigma influences or impacts on accessing community based mental health services it is necessary to analyse the various forms of stigma related to mental health. Literature reviewed identified four distinct types of stigma related to mental health including self-stigma, social stigma, professional stigma, and institutional stigma.[119]

3.2.1 Self Stigma and community based mental health

Self-stigma is described as the 'negative attitudes of an individual to his/her own mental illness and is also referred to as internalised stigma.'[120] The mere knowledge that society holds certain beliefs and views about persons with psychosocial and intellectual disabilities can have an impact on an individual even if the person has not been directly stigmatised.[121] Public perception itself can result in 'poor outcomes, such as failure to access treatment, disempowerment, reduced self-efficacy, and decreased quality of life.'[122] Labelling individuals based on their mental health conditions also contribute towards self- stigma. There is also a tendency to self-identify in other ways, as 'persons with lived experience', 'users and consumers of mental health services'.[123] In a study conducted by UCT on mental health community advocacy groups in 2019, persons with psychosocial and intellectual disabilities revealed that their self-confidence was threatened due to the stigma experienced by their family members because of the way society discriminated people on the basis of their mental health.[124] This had a direct bearing on their help seeking behaviour as they were more reluctant and fearful of being 'mocked' at if they tried to reach out for services.[125] Self- stigma can prevent individuals from seeking health care services even if it is available in the community.

The negative attitudes of health professionals towards persons with psychosocial and intellectual disabilities can have an impact on their adherence to treatment within health care facilities.[126] Self- Stigma can result in the individual withdrawing from any participation in the

[119] BK Ahmedani 'Mental Health Stigma: Society, Individuals, and the Profession' (2011) *Journal of Social Work Values Ethics* (2011) 4 at 12.
[120] MA Subu, DF Wati, N Netrida, V Priscilla, JM Dias, MS Abraham, S Slewa-Younan and N Al-Yateem 'Types of stigma experienced by patients with mental illness and mental health nurses in Indonesia: a qualitative content analysis' *International Journal of Mental Health Systems (2021).*
[121] PW Corrigan 'The impact of stigma on severe mental illness' (1998) *Cognitive and Behavioural Practice* 201 at 211.
[122] Subu et al (n 118).
[123] Discussion Paper 'A Rights-Based Approach to Disability in the Context of Mental Health' (2021) *United Nations Children's Fund* (UNICEF) 2021.
[124] T Davies, R Roomaney, C Lund, & K Sorsdahl 'Evaluation of an Advocacy Programme for Mental Health Care Users in South Africa: A Mixed Methods Study' (2021) *Community mental health journal*.
[125] Davies et al (n 122).
[126] Ahmedani (n117).

community, leading to self - isolation for fear of being victimised and ridiculed for being different from others.[127] The isolation itself can have a detrimental impact on the mental wellbeing of persons with psychosocial and intellectual disabilities and also reduce their chances of returning for medical treatment.[128] 'Persons with psychosocial disabilities' is the agreed upon term used by international human rights mechanisms and organisations of person with disabilities. This terminology is used to specifically reflect the social barriers to participation (rather than using medical terminology), 'placing the focus on the attitudinal and environmental barriers that restrict their equal participation in society.'[129] Article 1 of the CRPD seeks to uphold the inherent dignity of persons with disabilities.[130] The principles of inherent dignity, respect for differences and non- discrimination suggest that stigma is a violation of the rights of persons with mental disabilities.[131] WHO highlighted the need to combat stigma by developing appropriate measures in national mental health policies and legislation and also ensuring that anti- stigma programmes are implemented by CBOs.[132] Failure to include these measures into policy and legislation and making resources available for implementation by CBOs has been a significant barrier in ensuring that persons with mental disabilities receive rights based information from CBOs on a regular basis.

3.2.2 Social Stigma and mental health

Social stigma refers to the beliefs and attitudes of the broader community towards persons with psychosocial and intellectual disabilities as 'being less equal or are part of an inferior group.'[133] It is a belief system created to develop differentiation between those with disabilities and those who are able- bodied.[134] In the case of mental health, persons with psychosocial and intellectual disabilities are identified as those who are inferior to the rest of society.[135] Negative attributes and labels like 'dangerous,' 'unstable,' and 'crazy' are assigned to groupings of persons with psychosocial and intellectual disabilities as a means to distance

[127] Subu et al (n 118).
[128] Subu et al (118).
[129] Office of the High Commissioner for Human Rights (OHCHR)'Mental health and human rights' (2017) *Report of the United Nations High Commissioner for Human Rights* A/ HRC/34/32.
[130] CRPD (n 41).
[131] J Wogen & MT Restrepo 'Human Rights, Stigma, and Substance Use' (2020) 52 *Health and Human Rights Journal* 22.
[132] WHO World health report 'Mental health: new understanding new hope' (2001).
[133] Schneider (n 112).
[134] Schneider (n 112).
[135] J Crocker & N Lutsky 'Stigma and the dynamics of social cognition' in SC Ainlay, G Becker, LM Coleman (eds) *The dilemma of difference: A multidisciplinary view of stigma* (1986) New York Plenum Press.

and single out the broader community from such groupings.[136] 'This belief system may result in unequal access to treatment services or the creation of policies that disproportionately and differentially affect the population.'[137]

The concluding observations on South Africa by the CRPD Committee (2018) has raised concerns about the legal barriers in the MHCA which include issues of legal capacity, involuntary admissions and substitute decision making which is contrary to the human rights approach.[138] Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD)[139] provides measures that States need to consider in their efforts to ensure respect, protection and fulfilment of the rights of persons with disabilities as equal citizens before the law.[140] According to General Comment No 1, many states misunderstand Article 12 (Equal recognition before the law) of the CRPD, which specifically promotes the shift towards supported decision making, upholding the principles of autonomy, participation in the community, freedom to make decisions, and equality.[141] Substitute decision making which is based very much on the medical approach to disability, takes away the rights of persons with disabilities to make their own decisions, freely.[142] For years, persons with disabilities (especially persons with psychosocial and intellectual disability) were deprived and denied their right to exercise their legal capacity because legal capacity is confused with mental capacity.[143] This was clearly elaborated on by the CRPD Committee in the communication of *Zsolt Bujdoso and others v Hungary*[144] where the Committee found that the State of Hungary had violated the rights of six persons with intellectual disability who were placed under guardianship preventing them from participating in the electoral process.[145]These are clear examples of how community sentiment and stigma can lead to discriminatory policies and legislation reinforcing stigma and violating the rights of persons with psychosocial and intellectual disabilities.

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[136] Davies et al (n 122).
[137] Ahmedani (117).
[138] Convention on the Rights of Persons with Disabilities ` Concluding observations on the initial report of South Africa` UN Doc CRPD/C/ZAF/CO/1 (Concluding observations) of 23 October 2018 para 22(a).
[139] CRPD (n 41).
[140] Convention on the Rights of Persons with Disabilities 'General Comment No 1 on Equal recognition before the law' UN Doc CRPD/C/GC/1 (CRPD General Comment No 1) of 11 April 2014 para 1.
[141] General Comment No 1 (n 138) para 3.
[142] WHO World Health Report 2001 (n 130).
[143] L Series & A Nilsson 'Equal recognition before the law' in I Bantekas et al (eds) *The un Convention on the Rights of Persons with Disabilities: A Commentary* (2018) http://ebookcentral.proquest.com/lib/pretoria-ebooks/detail.action?docID=5567798 (accessed 21 July 2022) 354.
[144] *Zsolt Bujdoso and others v Hungary.*
[145] Communication No 4/2011 Zsolt Bujdoso and others v Hungary (Bujdoso case) views adopted on 9 September 2013 UN Doc CRPD/C/10/D/4/2011 (16 October 2013).

The international human rights instruments obligate state parties to ensure that persons with psychosocial and intellectual disabilities are entitled to the same rights as everyone on an equal basis with others.[146] Since the adoption of the Universal Declaration of Human Rights (Universal Declaration),[147] every human being including persons with psychosocial and intellectual disabilities are 'entitled to certain fundamental rights which include the right to health.'[148] The World Health Organisation's (WHO) definition of health as 'a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity,'[149] is consistent with the human rights approach to disability. The definition affirms the social model of disability in that mental health and wellbeing is not necessarily only about medical intervention but that it includes full integration into society that does not discriminate against persons with psychosocial and intellectual disability on the basis of a medical condition.[150] Article 25 of the CRPD stipulates that persons with disabilities have the 'right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.'[151] The human rights framework like the social model affirms that disability is a socially constructed concept and that it is the barriers in the environment and attitudes of people in society in their interaction with persons with impairments that hinder the participation of persons with mental disabilities in society on an equal basis with others.[152]

Since democracy, South Africa made a conscious effort to integrate mental health into the (PHC) system, to not only ensure parity with physical health but to also address the stigma related to mental health by including families and communities as part of the plan.[153] At a policy level, it was stated that 'at the community level, non-governmental and other grassroots organisations should be involved in the provision of mental health services.'[154] This was also followed by the adoption of a human rights focused mental health legislation which also promoted the integration of mental health into PHC system.[155] While the plans and intentions of government towards an integrated PHC system was to ensure greater access to health care

[146] CRPD (n 41).
[147] Universal Declaration of Human Rights (Universal Declaration) was adopted by the General Assembly of the United Nations on 10 December 1948 with UNGA Res 217 A (III) and entered into force on 22 April 1954.
[148] Amnesty International 'Human Rights of persons with Mental Disability in Bulgravia' (2002).
[149] WHO World Health Report 2001 (n 130).
[150] UNICEF Discussion Paper (n 121).
[151] Article 25 CRPD (n 41).
[152] 'Report of the Special Rapporteur 2017' (n 66).
[153] Mkhize & Kometsi (n 32) 103 at 107.
[154] White Paper for the Transformation of the Health System in South Africa (n 31).
[155] MHCA (n 10).

(including mental health) for all South Africans, very little provision was made to ensure that the PHC system was capacitated to deliver on the promises of policy and legislation.[156]

It is argued that South Africa has implemented a 'selective' PHC system (rather than a fully integrated system) which prioritises certain health conditions to the detriment of others.[157] National and global economic policies (which do not respect the human rights of persons with mental disabilities) have had a devastating impact on the implementation of a fully integrated PHC system.[158]Primary health facilities continue to follow a medical model of care providing medication to persons with psychosocial and intellectual disabilities with fewer opportunities for psychosocial counselling.[159] This places an enormous burden on CBOs to provide psychosocial rehabilitation services, skills development, day care and residential services to ensure that persons with psychosocial and intellectual disabilities are integrated into the community, however the partnership between government and CBOs is threatened by the lack of comprehensive implementation of policy and legislation to legitimise and adequately fund the significant role and function of CBOs.[160]

There is also affirmation that mental health is an integral part of overall health.[161] The WHO also declares 'the highest attainable standard of health as a fundamental right of every human being,'[162] making it clear that no one should be denied access to health care and more importantly that the right to health improves access to other socioeconomic rights.[163]

The United Nations right to health programme centres health as an inclusive right which is not only about being healthy or having access to medical treatment but extends to the underlying determinants of health which include 'access to safe and potable water and adequate sanitation, healthy occupational and environmental conditions, and access to health-related education and information, including sexual and reproductive health.'[164] A violation of a fundamental human right like the right to health has further ramifications on other human rights like the right to education, employment and living in the community.[165] Access to health

[156] Burns (n 26).
[157] Burns (n 26).
[158] Burns (n26).
[159] A Green 'An Introduction to health planning in developing countries' (1999) *Oxford: Oxford Medical Publications.*
[160] Mkhize & Kometsi (n 32) 106.
[161] 'World mental health report: transforming mental health for all' (n 1) 17.
[162] 'WHO Fact sheet' https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health.
[163] Covenant on Economic, Social and Cultural Rights (CESCR) was adopted by the General Assembly of the United Nations on 16 December 1966 with UNGA Res 2200A (XXI) and entered into force on 3 January 1976.
[164] CESCR (n 161).
[165] CRPD Concluding observations 2018 (n 136).

services is not only a medical provision (while medical intervention is a priority and also necessary), but includes a broader basket of services that should be available within a community setting to be provided by an array of stakeholders including CBOs.[166] Failure to make resources available to CBOs to ensure that these human rights obligations are met is another significant barrier to accessing community based mental health care for persons with mental disabilities.

The right to health discourse is featured in various international human rights instruments.[167] Within the African region, the African Charter of Human and Peoples Rights (ACHPR) also focuses on the right to health.[168] As mentioned earlier the Universal Declaration was the first human rights instrument to address the right to health as more than just access to medical care and services.[169] The human rights approach to disability, informed by the social model identifies social stigma as a significant barrier to accessing community based mental health care provided by CBOs due to the belief systems of government and decision makers that mental health is a health issue to be dealt with within the health care system only and that persons with psychosocial and intellectual disabilities are unable to participate in decision making about their mental health needs. The role of CBOs in addressing social determinants of health as part of the mental health care programme is ignored and not prioritised, depriving citizens of their right to the highest attainable standard of health.

3.2.3 Professional Stigma

Professional stigma refers to the attitudes of health care workers (including social workers) who may have stigmatised beliefs towards persons with psychosocial and intellectual disabilities.[170] Health care professionals have been reported to distance themselves from persons with more severe mental disabilities and show tendencies to interact less willingly than with persons with other health care conditions.[171] It is argued that health care professionals may even change their behaviour towards persons with psychosocial and intellectual disabilities once they learn of their conditions.[172] Stigma among health professionals develops the same

[166] CRPD Concluding observations 2018 (n 136).
[167] UN Committee on Economic, Social and Cultural Rights (CESCR) General Comment No 14 'The Right to the Highest Attainable Standard of Health (Art 12 of the Covenant' 11 August 2000,E/C.12/2000/4.
[168] The African Charter on Human and Peoples' Rights was adopted in 1981 by the 18th assembly of Heads of State and Government of OAU, and came in to force in 1986.
[169] Universal Declaration (n 145).
[170] Ahmedani (117).
[171] D Volmer, M Mäesalu, JS Bell 'Pharmacy students' attitudes toward and professional interactions with people with mental disorders' (2008) *International Journal of Social Psychiatry* 402 at 407.
[172] Ahmedani (117).

way as stigma is developed in society and that social upbringing and exposure in communities result in health professionals developing their own biases.[173]The UCT study on the Evaluation of an Advocacy Programme for Mental Health Care Users in South Africa also cited a few examples of how stigma was experienced by persons with psychosocial and intellectual disabilities among nurses working at community PHC clinics who refused to cooperate or provide services.[174] Stigma among health care professionals is a rather critical concern as it impacts on the rights of persons with psychosocial and intellectual disabilities in accessing mental health services in the PHC system that is meant to be available.[175] The stigma expressed by health care professionals can impact the health seeking behaviour of communities and lead to reduced efforts in seeking further services.[176] Studies conducted in certain districts in South Africa found that with the integration of mental health services into PHC system, there was a reluctance among nurses with clinical or psychiatric experience to address common mental disorders which was one of the main reasons why integration was considered in the first place.[177] This was due to nurses feeling that their professionalism was affected and further that they were not adequately trained to address common mental disorders.[178] Professional stigma is also related to health care professionals feeling that they were not consulted in terms of policy decisions which affect their day to day work.[179] The integration of mental health into the PHC system also means that nurses with specialised training are now expected to work as general nurses and their professional integrity is challenged which can also lead to professional indifference.[180] These attitudes affect how mental health care users are treated within the health care setting, how information is provided and whether the person is informed or referred appropriately to other services in the community (like CBOs) that can support and ensure that the person receives holistic care. Awareness and education about one`s own belief system regarding mental health is crucial in making sure that services are provided in a humane and dignified manner respecting the rights of persons with psychosocial and intellectual disabilities.

The professional staff employed by CBOs also experience professional stigma. Studies have shown that the remuneration of professionals employed by CBOs do not match salary

[173] Ahmedani (117).
[174] Davies et al (n122).
[175] SAHRC (n 51).
[176] Ahmedani (117).
[177] I Petersen 'Comprehensive integrated primary mental health care for South Africa: pipedream or possibility?' (2000) *Social Science & Medicine.*
[178] Petersen (n 175).
[179] I Petersen 'Primary level psychological services in South Africa: can a new psychological profession fill the gap? Health Policy Plan' (2004).
[180] Ditchman et al (n 115).

packages offered to government employees.[181] This has been a battle for decades.[182] CBOs lose well trained professionals to government departments regularly and struggle to train professionals on an ongoing basis.[183] Stigma related to professionals within and outside the mental health sector is a major barrier to accessing community based mental health services as it impacts on the quality of care that is provided within the health care setting and by CBOs. It is therefore important to ensure that sufficient provision is made to address professional stigma by allocating adequate budgets to recruit and train professional mental health staff to deliver quality mental health services.

3.2.4 Institutional Stigma

Institutional stigma refers to organisational policies and cultural practices towards persons that are stigmatised, like persons with psychosocial and intellectual disabilities.[184] This also includes legal frameworks that are designed to exclude certain sectors of the population.[185] The CRPD recognises that the right to the highest attainable standard of physical and mental health is dependent on access to health care.[186] It is cognisant of the structural barriers experienced by persons with disabilities in enjoying the rights and freedoms as equal human beings and remedies this obstacle by granting member states the right to afford persons with disabilities 'appropriate preferential treatment' so that they too can participate as equal citizens in society.[187] Persons with psychosocial and intellectual disabilities face several barriers in terms of employment, education and housing (living in the community).[188] These barriers will be examined in light of the support that CBOs provide to persons with mental disabilities.

a) Employment

Stigma towards persons with psychosocial and intellectual disabilities can lead to discrimination in the workplace.[189] Studies reveal that unemployment rates among those with psychosocial and intellectual disabilities can be as high as 90% often due to inconsistent behaviour, lack of trust or simple intolerance towards requests for reasonable accommodation

[181] M Renard & R Snelgar (2015) 'Correlating non-profit employees' level of salary satisfaction with their intrinsic rewards: A South African study' (2015) *African Journal of Reward.*
[182] Renard & Snelgar (n 179).
[183] Renard & Snelgar (n 179).
[184] Ahmedani (117).
[185] Ahmedani (117).
[186] CRPD (n 41).
[187] Convention on the Rights of Persons with Disabilities 'General comment No 5 (2017) on living independently and being included in the community' UN Doc CRPD/C/GC/5 (General Comment No 5) of 27 October 2017 para 1.
[188] General Comment No 5 (n 185) para 6.
[189] C Manning & PD White 'Attitudes of Employers to the Mentally Ill' (1995) *Psychiatric Bull.*

needs.[190] According to the CRPD reasonable accommodation includes necessary adjustments and accommodations to ensure that persons with disabilities can participate on an equal basis with others.[191] The experience of relapse among persons with psychosocial and intellectual disabilities results in exclusion from society and leads to difficulties in competing for high paying jobs.[192] Persons with psychosocial and intellectual disabilities need access to occupational training in the community to prepare for employment in the open labour market.[193] These services can be highly costly and inaccessible for the majority of the population.[194] Such barriers to employment impact on the rights of persons with psychosocial and intellectual disabilities to generate income and participate in the community.[195] CBOs provide much needed psychosocial support services that inform individuals about their rights in the workplace, how to deal with and cope with stressors in the workplace and also educate employers in terms of how to accommodate and create a healthy working environment. However, these programmes provided by CBOs are not recognised or supported by government and the private sector, wasting this untapped potential to ensure that persons with psychosocial and intellectual disabilities participate in the economy thereby reducing the high costs of relapse for the health system and the cost of unemployment for social security.[196]

Many persons with psychosocial and intellectual disabilities are unable to secure employment in the open labour market and depend on CBO run Protective Workshops which create a supported work-like environment within which individuals can learn new skills.[197] Poor investment by government and the private sector in these programmes result in these workshops not functioning optimally, and ineffective monitoring and lack of regulations can lead to abusive practices. Failure by the Department of Labour to recognise and address the needs of these communities by making provision for regulated protective or supported employment programmes leaves many without access to these services provided by CBOs.

b) Education

Reports note that many children with intellectual and psychosocial disabilities remain outside the school system which is a violation of the rights granted to children in the

[190] Manning & White (n 187).
[191] CRPD (n 41).
[192] Manning & White (n 187).
[193] Manning & White (n 187).
[194] Manning & White (n 187).
[195] Manning & White (n 187).
[196] D Besada, S Docrat & C Lund 'Mental health investment case for South Africa' (2021) 1 at 26.
[197] Besada, Docrat and Lund (n196) 28.

constitution.[198] Children with intellectual and psychosocial disabilities have been excluded from mainstream schools that are not equipped with the human and infrastructural resources to accommodate children with special needs.[199] As a result these children have been institutionalised without any long terms plans for secondary and tertiary education and skills development.[200] CBOs provide day care facilities for adults with intellectual disabilities who have been excluded from employment as they have do not have any qualifications for employment. The day care facilities provide educational programmes to empower these individuals to learn life skills that can assist towards independent living in the community. However, these programmes are poorly funded by government and policies poorly implemented[201].

While the Constitution specifically caters for children with disabilities to attend mainstream schools,[202] and the Education White Paper 6[203] spells out South Africa`s commitment towards inclusive education, studies show that there is still a resistance towards inclusive education as separate Special Needs Schools continue to exist 16 years later.[204] The Human Rights Watch report of 2015 noted that over half a million children with disabilities were not included in mainstream education.[205] Parents struggle to get children into mainstream schools that are in the community and as a result incur additional costs in transport and fees for admission into Special Needs Schools.[206] Provincial Departments of Education continue to direct funds towards Special Needs Schools which were meant to eventually feed into mainstream schools which would have been capacitated over the medium term, to receive all children and provide quality education to all.[207] There is sufficient evidence which shows that parents, teachers and caregivers continue to express fears about inclusive education which is believed to be moulded along the cultural and racial biases of the countries colonial history.[208] The litigation brought by the Western Cape Forum for Intellectual Disability (a CBO) against

[198] MA Winzer 'The History of Special Education: from Isolation to Integration' (1993)44 at 57.
[199] Manning & White (n 187).
[200] Manning & White (n 187).
[201] Winzer (n 198) 57.
[202] Article 9 Constitution (n 28).
[203] Department of Education 'White Paper 6: Special Needs Education - Building an inclusive education and training system' (2001) Pretoria Department of Education.
[204] D Donohue & J Bornman' The challenges of realising inclusive education in South Africa' (2014) *South African Journal of Education* 34(2).
[205] Human Rights Watch report https://www.hrw.org/report/2015/08/18/complicit-exclusion/south-africas failure-guarantee-inclusive-education-children (accessed 25 March 2022).
[206] Save the Children Inclusive Education in Zimbabwe video https://www.youtube.com/watch?v=AuMH2T_GAtI&t=3s (accessed 24 March 2022).
[207] SAHRC Report 'The Management and Rights of Learners at Special-Needs Schools Research Brief' (2018).
[208] Donohue & Bornman (n 203).

the Western Cape Department of Education revealed that the Education White Paper 6 policy document superficially presents a willingness on the part of the state to implement inclusive education, however in practice the state continues to practice segregation of children on the basis of disability exposing the institutional stigma still present within the education system. Ngwena, critically analyses the notion that inclusive education is a globalised ideal. [209] Upon interrogation it becomes clear that while African states have ratified and bought into this notion of inclusive education and have developed policies which reflect an intention to realise inclusive education, the poor domestic implementation reveals that Africa is not yet ready to accept persons with disabilities as equals in the education space. [210] States are encouraged to invest more in public and community programmes that 'facilitate the early detection and treatment of children's psychosocial, emotional and mental problems.'[211] Institutional stigma within the education system is a barrier for communities to access services provided by CBOs.

c) Housing

The right to accommodation is a basic human right which leads to a life of dignity. This right is guaranteed to 'everyone' in section 26 of the Constitution.[212] The poor socio-economic conditions, and barriers to accessing employment and education faced by majority of persons with psychosocial and intellectual disabilities, impacts on their ability to access housing in the community.[213] They are dependent on their families for accommodation. Section 3 of the National Health Act 61 of 2003, makes provision for the development of community mental health housing and day care services for persons with psychosocial and intellectual disabilities.[214] The provision of these services is believed to improve the reintegration of persons with psychosocial and intellectual disabilities into their communities and also contributes to the reduction of stigma. Residential and day-care facilities for persons with disabilities are mostly provided for by CBOs and licensed by the provincial departments of health.[215] While the state does make provision for subsidies for the care of persons with psychosocial and intellectual disabilities, these subsidies do not adequately cover the cost of living for these individuals which affect the quality of care and compromises their right to

[209] C Ngwena 'Western Cape Forum for Intellectual Disability V Government of the Republic Of South Africa: A Case Study of Contradictions in Inclusive Education' (2013) 1 *African Disability Rights Yearbook* 139-1.
[210] S Miles & N Singal 'The education for all and inclusive education debate: conflict, contradiction or opportunity?'(2010) 14 *International Journal of Inclusive Education* 1 9.
[211] Miles & Singal (n 216).
[212] Section 26 Constitution (n 28).
[213] L Chenwi 'taking those with special housing needs from the doldrums of neglect: A call for a comprehensive and coherent policy on special needs housing.' (2007) *Law Democracy and Development 1.*
[214] National Health Act 61 of 2003 (Act No 61 of 2003).
[215] WPRPD (n 15).

dignity.[216] The provision of residential and day care facilities came under much scrutiny following the Life Esidemeni tragedy when persons with psychosocial and intellectual disabilities were transferred to unlicensed facilities by the Gauteng Department of Health.[217]

The lack of understanding of the needs of persons with disabilities, rushed planning and inadequate funding allocation and lack of consultation with persons with psychosocial and intellectual disabilities is evidence of the stigma among public servants and discrimination towards persons with disabilities, not only in Gauteng but nationally.[218] Reducing stigma has been identified as an important factor that will improve the lives of those with mental health conditions.[219]

Article 19 of the CRPD on right to live independently and be included in the community promotes the opportunity of choice available to persons with disabilities in terms of how, where and with whom they choose to live within the community.[220] General Comment 5 on living independently and being included in the community noted that persons with psychosocial and intellectual disabilities, historically experienced social barriers to being included in the community on an equal basis with others.[221] One of the main principles of the CRPD (Article 3c) is 'effective participation and inclusion in society' in trying to achieve equality.[222] Article 19 focuses on giving choice to persons with disabilities, to determine how they want to participate and be included in the community.[223] There are long waiting lists of individuals who cannot access residential care provided by CBOs. The funding allocated by government to CBOs to provide residential care does not take into consideration all living costs related to being included into the community.[224] Studies have shown that poor inter-sectoral collaboration between government departments impact the quality of services that are provided by CBOs and that if CBOs are adequately supported by government, residential facilities can be made more accessible and affordable for persons with disabilities.[225]

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[216] WPRPD (n 15).
[217] MW Makgoba 'The report into the 'Circumstances surrounding the deaths of mentally ill patients: Gauteng Province' South Africa: Office of the Health Ombud 2017.
[218] Makgoba (n 217).
[219] O Catherine, I Egbe, C Brooke-Summer, T Kathree, O Selohilwe &I Peterson 'Psychiatric stigma and discrimination in South Africa: perspectives from key stakeholders' (2014)*BMC Psychiatry.*
[220] Article 19 of the CRPD (n 41).
[221] General comment No 5 (n 185).
[222] Article 3 (c) of the CRPD (n 41).
[223] Article 19 of CRPD (n 41).
[224] Makgoba (n217).
[225] Makgoba (n 217).

3.3 Investment and resource allocation for mental health services

According to Gureje and Alem, politics and economics determine how countries allocate resources for health care.[226] In South Africa, mental health services are poorly prioritised within the health care system.[227] Mental health in South Africa is the primary responsibility of the Department of Health and for decades the budget for mental health is directed predominantly to specialist mental health hospitals.[228] The attitudes (stigma) of health care professionals, political leaders and society (already discussed earlier) influences the decisions of policy makers leading to poor allocation of resources for mental health services in the community.[229] The MHPF listed resource allocation as one of the barriers to accessing CBO services as a larger proportion of the health budget is allocated to tertiary hospitals, which provide specialist clinical services only.[230] Despite the launch of the MHPF in 2013, the Life Esidemeni tragedy exposed the poor funding allocations towards community based residential and day care facilities that were found to be lacking in terms of capacity to provide dignified care in the community.[231] Another problem is that provincial government departments vary in their allocation of budgets towards mental health services, which is also reflected in the huge CBO subsidy disparity between provinces.[232] While inter-sectoral collaboration was also identified as a significant factor towards the successful implementation of community mental health services, it is not clear to what extent the departments of Social Development, Labour, Human Settlements and Education allocate resources towards CBO services.[233] Several international and national studies have found that it is more economical to invest in mental health care services than to not.[234] It is evident that South Africa still follows the trend of most LMIC where 'there exists an almost universal commitment to pay for hospitals, beds and medications instead of building a society in which everyone can thrive.'[235]The funding

[226] O Gureje & A Alem 'Mental health policy development in Africa' (2000) 479 *Bulletin of the World Health Organization* 78.
[227] Mkhize & Kometsi (n 32).
[228] L Robertson, MYH Moosa & FY Jeenah Strengthening of district mental health services in Gauteng Province, South Africa (2021) *South African Medical Journal* 1 at 1.
[229] N Sartorius 'Mental Health and Primary Health Care' (2008) 5 *Mental Health in Family Medicine* 75 at 76.
[230] MHPF (n 3).
[231] SAHRC (n 51)
[232] C Lund & AJ Flisher 'Norms for mental health services in South Africa' (2006) *Social Psychiatry Epidemiol* 7.
[233] SAHRC (n 51).
[234] S Docrat, D Besada, C Lund 'An Evaluation of the Health System Costs of Mental Health Services and Programmes in South Africa' (2019) *Alan J Flisher Centre for Public Mental Health*.
[235] Special Rapporteur (n 66).

practices for mental health services in South Africa is mostly biased towards the medical model of disability and is still heavily focused on impairment treatment rather than a human rights focus reflecting lack of implementation of current policy and legislation.[236]

The report of the Special Rapporteur on the Right of everyone to the enjoyment of the highest attainable standard of physical and mental health has acknowledged resource distribution and participation by vulnerable communities as additional social determinants that impact on states' abilities to meet obligations in achieving the right to health.[237] The rapporteur acknowledged the role of CBOs as vital partners in addressing stigma and discrimination in addition to the social determinants of mental health using available resources in the community.[238]

3.4 Lack of knowledge and understanding of mental health

For too long, research on mental health focused on the 'burden of disease,' which reinforced the medical model of care towards prioritising medical interventions for isolated conditions.[239] The high prevalence of stigma amongst health workers, persons with psychosocial and intellectual disabilities, the broader community and employers exposes the lack of information and understanding of mental health.[240] Stigma in mental health delays early help-seeking behaviour, which can lead to more severe conditions.[241] Studies reflect that there is very little understanding about mental health in communities, and little opportunity to create awareness of mental health.[242] A human rights focus to disability requires greater investment in educating individuals, families and communities about mental health as well as the needs of persons with disabilities. Education and awareness about mental health must also be language sensitive, given the vast cultural diversity in South Africa.[243] While the MHPF identifies stigma as a barrier to accessing mental health care in the community, there is no guidance on how stigma should be addressed using anti-stigma programmes for mental health.[244] CBOs are better placed within communities to implement awareness and education programmes as CBOs

[236] SAHRC (n 51).
[237] Special Rapporteur (n 66).
[238] Special Rapporteur (n 66).
[239] Special Rapporteur (n 66).
[240] Subu (n 118).
[241] Subu (n 118)).
[242] I Petersen & C Lund 'Mental health service delivery in South Africa from 2000 to 2010' (2011) *South African Medical Journal*.
[243] SAHRC (n 51).
[244] W Marais & I Petersen 'Health system governance to support integrated mental health care in South Africa: Challenges and opportunities (2015).

work directly with mental health care users who can share their experiences to educate communities. CBOs are not recognised as official bodies that can share help government to share credible mental health information.

3.5 Conclusion

Mental health is highly stigmatised and misunderstood and requires the urgent attention of policy makers, mental health professionals and communities at large. Despite progressive human rights based mental health legislation and policy, there is a lack of investment in mental health and an ongoing biased allocation of funds towards tertiary institutions depicting the medical model of intervention for mental health in South Africa. The lack of will to invest in human rights focused, community based mental health programmes and services reflects the stigma of decision makers towards CBOs that provide community based mental health services upholding the rights of persons with psychosocial and intellectual disabilities. Exploring good practice models implemented by other countries can provide solutions to the challenges in accessing community based mental health services in South Africa.

Chapter Four: Addressing the barriers to accessing community based mental health services provided by CBOs

4.1 Introduction

Stigma including self-stigma, social stigma, professional stigma, and institutional stigma can prevent access to community based mental health services provided by CBOs in South Africa. Poor financial commitment and investment towards policy implementation have delayed development and capacitation of CBOs to reach majority of citizens in need of mental health support.[245] Stigma, lack of investment and awareness programmes for mental health are significant barriers to accessing community based mental health services provided by CBOs. These barriers are not unique to South Africa. It is a national global problem and requires attention.[246] Global organisations like WHO, United for Global Mental Health, and the World Federation for Mental Health have already joined forces to provide guidance to governments all over the world so that mental health becomes a priority for all.[247] This chapter will examine some of the alternatives available to address the three main barriers identified (not all barriers can be addressed in this discourse), explore some of the best practice solutions used by CBOs in other countries to increase access to CBO services and conclude with recommendations for South Africa.

4.2 Recognising the role of NGOs/ CBOs in mental health legislation and policy

A major barrier to accessing mental health services provided by CBOs is the lack of recognition and provision for funding of social care services in mental health legislation and policy. WHO recognises CBOs as partners in non- health settings providing social services within a human rights approach.[248] CBOs operate within the social development space and are able to support persons with psychosocial and intellectual disabilities with 'relationships, family, employment, housing and education, leaving the clinical intervention to the health sector, but facilitating and ensuring adherence to treatment. [249] CBOs assist government to mobilise communities, providing much needed information, awareness, social services and skills development to improve the living conditions of persons with psychosocial and intellectual disabilities in communities.[250] Inter-sectoral collaboration must be embedded in

[245] Docrat et al (n 230).
[246] 'World mental health report: transforming mental health for all' (n 1) 188.
[247] 'World mental health report: transforming mental health for all' (n 1) 186.
[248] 'World mental health report: transforming mental health for all' (n 1) 188.
[249] Department of Social Development: Policy on the Funding of Non-Government Organisations for the Provision of Social Welfare and Community Development Services (2014).
[250] Department of Welfare and Population Development, 1997

policy and legislation ensuring that social services are included in mental health care.[251] This will also ensure that other government departments also prioritise mental health so the pool of resources for mental health is shared and increased at the same time.[252] While mental health legislation and policy includes the role of CBOs in mental health service delivery, implementation is lacking and there is a need to regulate the role of CBOs as partners in the provision of community based mental health services. The Investment case report recommends that government include a dedicated budget for mental health within the National Health Insurance budget to among others, support the capacitation of mental health CBOs that provide day care, residential and rehabilitation support services to persons with psychosocial and intellectual disabilities.[253] Many high income countries like Canada, England and Australia have included budgets for CBOs to provide mental health care in the community to complement the services provided by the health sector.[254]

4.3 Anti- Stigma programmes to address the negative attitudes of communities, work places and mental health professionals to promote inclusion in the community

There is much evidence that show that anti-stigma programmes can reduce discriminatory attitudes towards persons with mental health conditions and improves society`s knowledge about mental health. Various strategies have been shown to be effective like educational programmes, contact based education programmes involving persons with psychosocial and intellectual disabilities and advocacy campaigns towards institutions that have discriminatory policies.

Peer support programmes

The involvement of persons with psychosocial and intellectual disabilities in providing peer support within communities is an empowering initiative that is used globally and has shown positive outcomes.[255] Having persons with disabilities share their experiences and challenges is not only self- empowering but also provides opportunities to witness persons with disabilities as positive role models breaking stigmatised perceptions. This intervention has also been implemented by CBOs in South Africa and should be supported by government.[256] An excellent good practice peer support programme is currently provided in Kenya, where persons

[251] 'World mental health report: transforming mental health for all' (n 1) 239.
[252] 'World mental health report: transforming mental health for all' (n 1).
[253] Docrat et al (n 230).
[254] 'Guidance on community mental health services: promoting person-centred and rights-based approaches' Geneva: World Health Organization (2021).
[255] Guidance on community mental health services: promoting person-centred and rights-based approaches'(n 254).
[256] SAHRC (n 51)

with psychosocial disabilities have started peer support groups since 2012. The community groups function independently of the mental health system and do not belong to any larger institutionalised groups.[257] Users and Survivors of Psychiatry Kenya (USPK) is a national membership organisation that sets up support groups and also provides virtual support using WhatsApp.[258] Persons with disabilities are supported to educate communities about disability related issues. The organisation first relied on donor funding and since 2016, is supported by government funding. Empowerment programmes focus on autonomy, decision making, mental health care and treatment, and relationship building to achieve mental wellbeing. 'These support groups are registered with the Ministry of Labour, Social Protection and with the National Council of Persons with Disabilities.'[259] This programme reflects the political will and support of policy and decision makers investing resources in MHCU led CBOs to break the stigma around mental health and increase access to community based mental health services.

Education and awareness programmes

To address the negative attitudes and discriminatory behaviour among duty bearers, public servants and communities require a well-structured, multi-sectoral mental health education strategy that must also involve persons with disabilities, be culturally sensitive and promote a human rights based approach to mental health.[260] Large scale national campaigns using media including social media have been very effective among high income countries like England, Canada and Australia where government has taken the lead to fund CBOs to participate in these campaigns to reach grass roots communities.[261] Low cost campaigns are also possible in LMIC where governments can provide support to CBOs already undertaking such campaigns increasing the visibility of CBOs so that communities can access the services provided by CBOs.[262] CBOs can also work closely with local radio stations to share information about mental health similar to the programme undertaken by USPK where information about mental health is shared by MHCU using local community radio stations.[263]

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[257] *Users and Survivors of Psychiatry Kenya 'The Role of Peer Support in Exercising Legal Capacity'* (USPK) *Nairobi, 2018.*
[258] USPK (n276).
[259] USPK (n276).
[260] 'World mental health report: transforming mental health for all' (n 1) 239.
[261] 'Guidance on community mental health services: promoting person-centred and rights-based approaches' (n 254).
[262] USPK (n276).
[263] USPK (n276).

Advocacy campaigns

Globally, advocacy for the human rights approach to disability resulted in the adoption of the CRPD.[264] Advocacy campaigns have also been effective in tackling institutional stigma like poor working conditions, educational barriers for persons with disabilities and also addressing the lack of housing for persons with psychosocial and intellectual disabilities. Informing and educating persons with disabilities about their rights using instruments like the CRPD can help them understand their rights and how to advocate for better services in the community. Mobilising persons with disabilities into self-advocacy groups is empowering in that these groups can also be used to train mental health professionals, employers, educators and other service providers as well as participate and contribute towards policy reform. In the workplace, CBOs can be used to train employers on the rights of persons with disabilities to reasonable accommodation measures, how to improve the mental wellbeing of all staff and also break stigma of employees and managers towards persons with disabilities. In the education space, advocacy for mainstream education for all children with disabilities has already started.

Advocacy campaigns facilitated by CBOs can also challenge government departments to improve policy and services for persons in need of residential care services. While South Africa does make provision for residential care services provided by CBOs, the quality of care is of concern and does not comply with Article 19 of the CRPD. Many of the residential facilities provided by CBOs (while licenced and approved by the Department of Health) are described as long term institutions that do not allow for independent living. South Africa can learn from good practice models in other countries that promote supported living services like the 'Home Again' programme in India.[265] This is a supported, inclusive living programme in Chennai, India which makes available housing and necessary support and care options for persons with more severe mental health conditions and psychosocial disabilities.[266] This programme was initiated by a non-profit organisation (The Banyan) to address the issues of homelessness and poverty. Home again 'accepts people who have been in long-term institutional care, with untraceable addresses, requiring long-term care who have been rejected by their families, or do not want to return home.'[267] Rental homes within urban and rural

[264] CRPD (n 41).
[265] 'Home Again' (n 254).
[266] Guidance on community mental health services: promoting person-centred and rights-based approaches' Home Again Chennai India (n 254).
[267] Guidance on community mental health services: promoting person-centred and rights-based approaches' Home (n 254).

communities provide housing and support services for four to five persons with mental health conditions who have full autonomy in the belief that 'social mixing and access to experiences are essential, not just for recovery from distress or trauma, but to live a good life.'[268]

South Africa has a huge housing shortage and mental health CBOs have been licensed by the Department of Health to provide residential care to persons with disabilities. The subsidies paid to these CBOs by government does not cover the cost of ensuring decent living conditions exposing the 'apartheid era' stigma and discriminatory attitudes of the current government and its officials, which result in poor investments in community based mental health services.[269] CBOs are forced to raise funds to provide decent, nutritious meals for persons with disabilities and are not respected as equal partners in the provision of community based mental health services. The 'Home Again' model is an excellent example of how persons with psychosocial and intellectual disabilities can be integrated into communities with the proper support of government and inter-sectoral collaboration among government departments.

4.4 Increasing investment for community based mental health services

Investment is mental health has been the second significant barrier to mental health service development and implementation. Human rights focused policies and legislation oblige states parties are to protect persons with intellectual and psychosocial disabilities by ensuring that 'low cost' programmes and policies are in place and implemented without compromising the quality of care.[270] Following an investigation into the mental health system in South Africa, the National Department of Health commissioned an investigation into the full costs for mental health services with the view of making provision for mental health services within the National Health Insurance Scheme.[271] This reflects a commitment towards universal health coverage for persons with mental health conditions ensuring greater access to mental health care and services for the uninsured population.[272] Including the costs of CBO mental health services will ensure that more people will have access to mental health care in the community

[268] Guidance on community mental health services: promoting person-centred and rights-based approaches' (n 254).
[269] SAHRC (n51).
[270] CRPD (n 41).
[271] Docrat et al (n 230).
[272] Docrat et al (n 230).

and also ensure that the care and services provided are of a high standard.[273] The study revealed that increasing investment in mental health will reduce the cost of health care in the long term, improve the socio economic conditions of the majority of citizens, reduce the cost of absenteeism in the workplace, improve educational outcomes of all children and also improve the general wellbeing of communities.[274] The benefits of increasing investment in mental health far outweigh the cost of the investment. By including mental health budgets into the NHI will also address the disparity of funding allocated for mental health services in the different provinces.

Investing in mental health is best implemented with policy reform. As South Africa embarks on reviewing the MHPF, it will be important to develop a programme that ensure funding is directed towards community based services. This practice was implemented in Peru since 2013, where funds were diverted from tertiary hospitals to community based services.[275] By 2020, Peru has seen more people access community based services by ensuring implementation of policy.

Investment in training of health and social care professionals and lay counsellors in mental health is an excellent opportunity to build capacity and skill to provide community mental health services. Ongoing training is essential to address stigma as well as system changes. Investing in mental health human resources is necessary in all settings including teachers, social workers, human resource personnel and employees in the private sector, police and legal professionals as it will strengthen the mental health system.

4.5 Prevention and promotion of mental health

Prevention and promotion of mental health looks at ways in which risks for mental health can be identified and strategies developed to reduce those risks. Lack of knowledge about mental health and the needs of persons with psychosocial and intellectual disabilities among families, communities, health care professionals, employers and teachers has been the third significant barrier to accessing community based mental health services.[276] It is therefore necessary to look at strategies or interventions that are available to address the poor literacy around mental health.

[273] Besada, Docrat and Lund (n196) 32.
[274] Besada, Docrat and Lund (n196) 28.
[275] World mental health report: transforming mental health for all' (n 1) 127.
[276] 'World mental health report: transforming mental health for all' (n 1) 65.

Multi-sectoral collaboration has already been identified as an intervention to address investment in mental health and this strategy can also be used to promote mental health in the various other non-health sectors.[277] The health sector could engage in working with other sectors to introduce promotion and prevention programmes like mental awareness days. Universal and global programmes can also be introduced like the international suicide prevention awareness.[278] Such a programme can introduced in various sectors like schools, workplaces and among frontline health care workers where stress is a huge risk factor.

Promotion and prevention interventions must also consider the needs of persons with psychosocial and intellectual disabilities to access mental health information so that informed decisions can be made in terms of treatment and services to achieve mental wellbeing. To address the mental health needs of young children and adolescents the educational institutions can implement mental health information as part of the curriculum so that much diverse and mental health tolerant societies are ensured. There is much literature about the benefits of mental health promotion, in reducing stigma and discrimination towards persons with psychosocial and intellectual disabilities.[279]

According to the WHO, health promotion is about learning how to practice a healthy lifestyle that will ensure mental health is preserved.[280] This is rather significant given that even those who have not been diagnosed with a mental health condition can benefit from mental health promotion and assist with early identification of symptoms. The Act- Belong-Commit (ABC) campaign in Australia is an excellent example of how mental health can be introduced to the general population by encouraging people to take action to ensure mental wellbeing.[281] People are much aware of the importance of physical fitness and the ACT campaign is now encouraging mental wellbeing by encouraging people to be more mindful of their mental health by taking steps to understand what is mental health, get involved with others to build healthy relationships and to have a sense of purpose. This campaign uses social media to share mental health information and also used community based CBOs to spread the campaign in local communities.[282] The campaign has also been adopted by several schools to promote mental health information among school children.

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[277] 'World mental health report: transforming mental health for all' (n 1) 73.
[278] 'Live Life: an implementation guide for suicide prevention in countries. Geneva: World Health Organization' (2021).
[279] WHO 'Promoting mental health concepts, emerging evidence, practice summary report' (2004).
[280] WHO 'Promoting mental health concepts, emerging evidence, practice summary report' (n 285).
[281] https://www.actbelongcommit.org.au/ (accessed 24 August 2022).
[282] 'Act-Belong-Commit' (n 261).

4.6 Recommendations for consideration and implementation in South Africa

While South Africa had already taken steps to ensure that mental health policy and legislation follow a human rights approach to mental health care and services, policy and legislation are in need of urgent review to ensure that it complies fully with the CRPD. As mental health policy and legislations are reviewed the following recommendations must be considered:

- The role of CBOs must be incorporated as essential mental health services to address the social determinants of mental health
- Mental health stigma and discrimination to be included as a violation of the rights of persons with psychosocial and intellectual disabilities
- Anti-stigma programmes to be embedded in all sectors including education, housing and employment
- Persons with disabilities to be prioritised in terms of education and employment programmes to ensure that they are given opportunities to improve their socioeconomic conditions
- Independent living programmes are aligned to the CRPD to ensure that persons with psychosocial and intellectual disabilities can live and participate in the community

4.7 Conclusion

The role of CBOs in providing social care mental health services has been neglected for too long. CBOs are an integral part of community based mental health care and services and contribute immensely towards the integration of persons with psychosocial and intellectual disabilities into communities. CBOs are able to bring various sectors together to provide holistic mental health services to persons with disabilities. CBOs must be acknowledged within mental health policy and legislation central role-players in the right to health, capable of networking with all sectors to ensure a holistic approach to enable persons with psychosocial and intellectual disabilities to achieve their recovery goals and live a more satisfying and meaningful lives. Capacitation of community based organisations must be prioritised to ensure that these organisations are accessible and available to provide much needed mental health services to all communities.

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