# REPORT OF THE NATIONAL INVESTIGATIVE HEARING INTO THE STATUS OF MENTAL HEALTH CARE IN SOUTH AFRICA

14 and 15th November 2017







The Hearing Panel: (left to right) Commissioner Adv. Bokankatla Joseph Malatji, Commissioner Angie Makwetla, Chairperson Adv. Bongani Majola, and Professor Katherine Sorsdahl

# **Acknowledgements**

The National Hearing on the Status of Mental Health Care in South Africa was chaired by the Chairperson of the South African Human Rights Commission, Professor Bongani Majola. In addition, the panel consisted of Ms. Angie Makwetla, Commissioner of the South African Human Rights Commission, Adv. Bokankatla Joseph Malatji, Commissioner of the South African Human Rights Commission and Professor Katherine Sorsdahl, Codirector of the Alan J. Flisher Centre for Public Mental Health at the University of Cape Town.

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# List of Acronyms

APA American Psychiatric Association

APC Adult Primary Care

CBO Community-Based Organisation

CESCR Committee on Economic, Social and Cultural Rights

CHW Community Health Worker

CPD Continuing Professional Development
CRC Convention on the Rights of the Child

CRPD Convention on the Rights of Persons with Disabilities
CRPD Committee on the Rights of Persons with Disabilities

Committee

DBE Department of Basic Education

DCS Department of Correctional Services

DHS Department of Human Settlements

DMHT District Mental Health Team

DOJCD Department of Justice and Constitutional Development

DPO Disabled Peoples' Organisation
DSD Department of Social Development

DSM V Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

DTT Deinstitutionalisation Task Team

**EEA** Employment Equity Act

GDOH Gauteng Department of Health

GMHMP Gauteng Mental Health Marathon Project

HHE Head of Health Establishment

HPCSA Health Professions Council of South Africa

HPRS Health Patient Registration System

HRH Human Resources for Health

ICESCR International Covenant on Economic, Social and Cultural Rights

ISHP Integrated School Health Program

IUSS Infrastructure Unit Support System

MEC Member of the Executive Council

MHCA Mental Health Care Act
MHCU Mental Health Care User

NDOH National Department of Health
NDP National Development Plan

NDPP National Director/ate of Public Prosecutions

NDRP National Disability Rights Policy NGO Non-governmental Organisation

NHA National Health Act

NHI National Health Insurance

NMHPF National Mental Health Policy Framework and Strategic Plan 2013-2020

NSLA National Strategy for Learner Attainment

OHO Office of the Health Ombudsman

OHSC Office of Health Standards Compliance

OSD Occupation Specific Dispensation

PEPUDA Promotion of Equality and Prevention of Unfair Discrimination Act

PHC Primary Health Care

PMB Prescribed Minimum Benefits

PRIME Programme for Improving Mental Health Care
SADAG South African Depression and Anxiety Group
SAFMH South African Federation for Mental Health
SAHRC South African Human Rights Commission
SALRC South African Law Reform Commission

SAPS South African Police Service

SASH South African Stress and Health Study

SIAS Screening, Identification, Assessment and Support

SIU Special Investigating Unit
UHC Universal Health Care
WHO World Health Organisation

# **FOREWORD**

he realisation of human rights is a complex topic that does not lend itself to axiomatic answers. Nowhere is this truer than when the rights of a marginalised section of the population are in question. In South Africa, we are faced with numerous human rights questions on a daily basis. Yet, even by those standards, the events that precipitated this inquiry were particularly abject.

The tragic loss of life following the discharge of mental health care users from the Life Esidimeni facility evoked a public outcry and led to widespread calls for further investigation, not only into the circumstances in that particular sequence of events but also, in relation to the broader mental health care system in this country.

This report represents the culmination of such a systemic inquiry. It highlights the varying deep-rooted challenges that characterise the mental health care system in South Africa, pointing to a chronic and systemic neglect, coupled with mismanagement and a dire lack of resources. Ultimately, the report does not make pronouncements on the Esidimeni tragedy, but it should not be lost on readers that the systemic failures referred to herein were instrumental in the horrific and needless deaths of over 100 mental health care users in that incident.

In presenting this report, the South African Human Rights Commission seeks to contribute to positive change in the mental health care landscape in South Africa, through continuous engagement relating to the report's findings, monitoring of the implementation of the recommendations contained herein and advocacy to support systemic change.

We acknowledge those whose lives were lost and their families, and undertake to ensure that such tragic events are never visited upon mental health care users in South Africa ever again.

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# 1. KEY FINDINGS

- The numerous human rights concerns that have been highlighted in this investigation can be said to arise out of a prolonged and systemic neglect of mental health at the level of policy implementation. Throughout the investigation, lack of resourcing, lack of technical capacity and possibly even lack of concern for the welfare of people with intellectual and psychosocial disabilities have arisen as root causes for system-wide failures to protect and promote the rights of this group.
- 2. South Africa needs to make substantial progress on numerous fronts in order for the country to meet its obligations in terms of the Convention on the Rights of Persons with Disabilities (CRPD). These include on the legislative front, where national disability rights legislation has been recommended; on awareness-raising of the rights of people with intellectual and psychosocial disabilities; and on economic and social rights such as education and health care.
- There is considerable under-investment in mental health by the South African government. The National Mental Health Policy Framework and Strategic Plan (2013 2020) (NMHPF) states that 'mental health care services should have parity with general health services'. This is not being realised. Considering the numerous demands placed on South Africa's health system, a budgeting approach is required that takes into account prevalence and the burden of mental conditions and intellectual disability. This budgeting should also consider the broader communities in which people living with psychosocial and intellectual disabilities live and inputs from other departments to achieve a holistic and inclusive service package. Particular attention should be paid to rural communities to ensure that budgets are not concentrated in urban areas and directed at psychiatric facilities only. There seems to be a major disconnect between the various sectors involved in mental health, including Health, Social Development, Education, Housing, Transport and Labour.
- 4. Comprehensive implementation of the NMHPF has not yet occurred. The Mental Health Directorates, established by the Act, are functioning in only some parts of the country, and have not substantially contributed to increased resources for mental health services. Similarly, District Mental Health Teams (DMHTs) who are responsible for planning and coordinating mental health services at the district level, have not been appointed. Overall, provincial departments made little progress on implementing the provisions of the NMHPF, and have consistently failed to allocate sufficient resources for the provision of mental health services. The disparate state of budgets across provinces and the lack of costed and budgeted strategic plans in most provinces is a major concern. This calls into question the budgeting guidance provided by the NDOH and the ability of provincial departments of health to implement the NMHPF.
- Although the Mental Health Policy Framework and Strategic Plan (2013 2020) emphasizes the value of a primary healthcare approach in reducing the treatment gap, the provision of mental health services seems to focus on care in psychiatric hospitals. The largest proportion of mental health budgets and the largest allocation of mental health professionals continues to be in specialist psychiatric facilities. This is despite the deinstitutionalisation that has already taken place in South Africa, the large burden of common mental conditions in the country, and the CRPD and the NMHPF recommending a shift toward primary care and community based care. It further suggests that a biomedical approach continues to dominate in the South African mental health care landscape. While psychiatric facilities do play an important role in the provision of health care services, the state is not making sufficient strides in the adoption of a rights-based approach to mental health care, particularly in primary healthcare and community settings.
- The GMHMP has illustrated that deinstitutionalisation is a process that requires numerous interventions in various sectors to actualise the rights of people living with intellectual and psychosocial disabilities. Lessons from international experience show that deinstitutionalisation can only work if the money follows the MHCU into the community. The GMHMP has highlighted that the model of deinstitutionalisation adopted by the GDOH was not in keeping with a rights-based approach to mental health care and did not undertake interventions to support their well-being in community-based settings. Haphazard licensure of NGOs and lack of consultation with MHCUs and their caregivers are further evidence in support of this finding.

- 7. Many barriers to providing mental health services were highlighted and were particularly problematic in rural areas. These include a lack of infrastructure, lack of HRH, and medication stock outs. The stigmatisation of people with psychosocial and intellectual disabilities emerged as a key barrier. Stigma and discrimination in communities, health facilities, schools and institutions of higher education was reported as a significant barrier to the inclusion of people living with intellectual and psychosocial disabilities.
- 8. Participation of MHCUs in their treatment is a central component of a rights-based approach to mental health care. For this reason, the slow pace of instituting structures such as stakeholder forums is of major concern. As an example, the empowerment modules implemented by the SAFMH have only reached four provinces thus far, due in large part to resource constraints, is noted with concern.
- **9.** Effective implementation of a rights-based approach to mental health requires an emphasis on the social determinants of mental health and well-being. This means engaging with various stakeholders to consider ways in which effective participation and inclusion of people with psychosocial and intellectual disabilities can be realised, examining barriers to social, cultural and economic inclusion and considering ways in which these forms of exclusion impede human rights and negatively impact on mental health.
- O. Services for children and adolescents are neglected. There is an urgent need to address the needs of children and adolescents with intellectual and psychosocial disabilities. While mental health overall is a neglected area, this particular sub-field is especially under-prioritised, with the result that violations of the rights of this group are perpetrated regularly in the form of cruel, degrading and inhumane treatment that places them at risk for abuse. South Africa is in direct contravention of the Constitution and the CRC in this regard. The rollout of the ISHP is an important step, but high numbers of children with disabilities not enrolled in school and the shortage of beds in existing facilities specifically for children and adolescents with intellectual and psychosocial disabilities remain a concern. A rights-based approach would suggest that the mere adding of these beds would be insufficient, however, as more needs to be done to integrate these affected persons into their communities and to provide appropriate community-based services using hospitalisation only as a last resort. It will be essential to develop community-based rehabilitation and psychosocial rehabilitation services to implement the integration of children and adolescents into their communities. This is likely to require dedicated rehabilitation staff which are available even in rural areas.
- The state of mental health services in the criminal justice, forensic and correctional systems in South Africa is particularly poor. It is clear that rights violations have occurred in several instances. The incarceration in prisons of 'state patients' and ongoing challenges within the criminal justice system of securing support for people living with psychosocial and intellectual disabilities are examples of this reality. Likewise, rates of suicide in prison are unacceptable and will require urgent intervention.
- 12. Broader conversations about law reform of instruments such as the MHCA and the Electoral Act are required. Particularly in light of their potential contravention of the CRPD and in light of ongoing debates regarding matters such as legal capacity.

# 2. INTRODUCTION AND BACKGROUND

# The mandate of the South African Human Rights Commission

he SAHRC is a National Human Rights Institution (NHRI) established in terms of section 181(1)(b) of the Constitution of the Republic of South Africa, 1996 (the Constitution). Its mandate is to promote respect for human rights and a culture of human rights; promote the protection, development and attainment of human rights; and monitor and assess the observance of human rights in the country. In carrying out this mandate, the Commission is empowered by section 184 (2) of the Constitution to investigate and report on the observance of human rights; to take steps to secure appropriate redress where human rights have been violated; to carry out research; and to educate. Further powers and functions of the Commission, including the power to investigate any alleged violation of human rights either upon receipt of a complaint or on its own initiative, are elaborated in the South African Human Rights Commission Act, 2013. In terms of section 13(1)(a)(i) of the Act, "[t]he Commission is competent and is obliged to make recommendations to organs of state at all levels of government where it considers such action advisable for the adoption of progressive measures for the promotion of human rights." It is within the ambit of this framework that the SAHRC resolved to hold a national investigative hearing on the status of mental health care in South Africa.

# The Esidimeni tragedy/Gauteng Mental Health Marathon Project and the recommendation of the Health Ombud for a systemic review

Through a contract with the Life Healthcare group, the National Department of Health (NDOH) and, subsequently, the Gauteng Department of Health (GDOH) had been subsidising institutionalised care for people with psychosocial and intellectual disabilities, an arrangement that ended on the 30<sup>th</sup> of June, 2016. In anticipation of the end of this contract, an estimated 1,371 MHCUs were rapidly transferred from the Life Esidimeni facility to hospitals and non-governmental organisations (NGOs), some of which were unlicensed, in a process that came to be known as the Gauteng Mental Health Marathon Project (GMHMP).<sup>1</sup>

Following reports of neglect, abuse, under-capacitation and under-resourcing, the press and civil society began noting that several MHCUs who had been transferred had died in the process. The exact number of deaths escalated from an initial figure of 36 to over 70 and the Minister of Health requested the Office of the Health Ombud (OHO) to investigate the circumstances surrounding these deaths. This investigation placed the figure at '94+'.² In November 2017, the figure was reported to be 143.³ In February 2018, it was reported that 49 of the MHCUs transferred out of the Life Esidimeni facility were still unaccounted for.⁴

Office of the Health Ombud. (2017). Report into circumstances surrounding the deaths of mentally ill patients: Gauteng province. https://www.scribd.com/document/338095858/Esidimeni-Report#from\_embed

<sup>&</sup>lt;sup>2</sup> Ibid

<sup>&</sup>lt;sup>3</sup> Child K. (2017). New number of Esidimeni dead-143. https://www.timeslive.co.za/news/south-africa/2017-11-10-new-number-of-esidimeni-dead-143/

Timeslive. (2018). Police find 8 more missing Esidimeni patients, says Bloom. https://www.timeslive.co.za/news/2018-02-20-police-find-8-more-missing-esidimeni-patients-says-bloom/

The full report of the OHO's investigation, entitled 'The Report into circumstances surrounding the deaths of mentally ill patients: Gauteng Province' has since been released, citing various systemic failures, stating that various human rights violations occurred in the unfolding of the GMHMP, but noting that human rights concerns are also prevalent in the broader mental health care system in South Africa.

Several of the recommendations from the OHO's report bear mentioning here, in the context of examining questions of accountability and the realisation of human rights. The recommendations made by the OHO included the re-assessment of all NGOs which housed MHCUs transferred out of Life Esidimeni and the removal of those MHCUs transferred from NGOs and CBOs deemed non-compliant with basic norms and standards. As comprehensive guidelines did not exist for standards, the OHO recommended that these be drafted immediately. It is important to note that these do not fall within the scope of the Hearing.

The OHO also recommended that the Minister of Health request the SAHRC to 'undertake a systemic review of human rights compliance and possible violations nationally related to mental health'. Upon receipt of such a request from the Minister, the SAHRC concluded that a national investigative hearing to examine numerous systemic issues that relate to the human rights of people with psychosocial and intellectual disabilities would be in the public interest.

# Purpose of the hearing

The Esidimeni tragedy was a key precipitant for the SAHRC's hearing. Recognising the significant human rights issues raised by this incident, the hearing nonetheless considers mental health more broadly, focusing on the systemic, social, cultural, political and economic concerns that affect the lives of MHCUs and that impede the full realisation of their rights.

Whereas the focus of the OHO was the deaths that occurred in the unfolding of the GMHMP and on the circumstances at political and administrative levels that coalesced to allow for the tragedy to take place, the Commission's hearing is intended to capture challenges and opportunities in the broader mental health care system. More importantly, the Commission's central intent is somewhat different, in that it is explicitly rights-oriented, taking into account the need for a rights-based approach to mental health care and emphasising the centrality of those most affected rather than the necessary but divergent focus on governance and process issues as adopted by the OHO.

Importantly, other processes have also emerged that relate to the Esidimeni tragedy, in particular various stakeholder engagements by civil society bodies and the arbitration hearing chaired by Former Deputy Chief Justice Dikgang Moseneke.<sup>6</sup> In July 2017, the President also authorised an investigation by the Special Investigations Unit (SIU) which may result in criminal charges being brought.<sup>7</sup> These, too, focus specifically on a single incident, and, while they do have significant human rights implications, they differ from the

<sup>&</sup>lt;sup>5</sup> OHO, as above.

<sup>&</sup>lt;sup>6</sup> Nicolson G. (2017). Life Esidimeni: Arbitration highlights government culpability. https://www.dailymaverick.co.za/article/2017-10-31-life-esidimeni-arbitration-highlights-government-culpability/#.Wky7rVWnHIU

Shange N. (2017). Zuma authorizes Special Investigating Unit probe into Life Esidimeni tragedy. https://www.timeslive.co.za/politics/2017-07-04-zuma-authorises-special-investigating-unit-probe-into-life-esidimeni-tragedy/

SAHRC's mandate, which is to focus on the broader mental health landscape in South Africa and which arises directly out the Esidimeni tragedy and the request from the Minister of Health.

The aims of the hearing did, in some respects, overlap with the other processes identified, in that the Commission was seeking accountability and investigating, among others, an incident that violated various rights, most notably the right to life. However, what the SAHRC's hearing was seeking to capture was a picture of the lived experiences of all people with psychosocial and intellectual disabilities in South Africa, taking into account their economic, social, cultural, civil and political rights. Therefore, while various endeavours have addressed some of these overlapping issues, they should be considered complementary exercises rather than substitutions or competing findings.

### THE OBJECTIVES OF THE SAHRC HEARING WERE TO:

- a) systematically monitor and document, nationally, the plans and measures to implement the deinstitutionalisation model preferred by South Africa in respect of that model's alignment with human rights norms and standards;
- b) consider the coherency of the legislative and policy environment from a rights based perspective and recommend the adoption of legislative measures that will promote the respect for the human rights of persons living with mental conditions;
- c) report any violations and, where necessary, take steps to secure appropriate redress;
- d) raise awareness, nationally, and promote advocacy of the human rights of MHCUs as well as the Constitutional imperatives that require the human rights of everyone to be respected, protected and promoted;
- e) to create awareness of applicable legislation and remedies to empower those affected by stigma and discrimination in the context of mental health; and
- f) engage with stakeholders and duty-bearers on the various ways in which the rights of people with psychosocial and intellectual disabilities in South Africa can be advanced.

# Defining mental health and the rights-based approach to mental health

### **Defining mental health**

The World Health Organisation (WHO), of which South Africa is a member, defines mental health as 'a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.'8 As such, mental health is not merely the absence of illness or disease.

Mental disorders are referred to as: "disturbances of thought, emotion, behaviour, and/or relationships with others that lead to significant suffering and functional impairment in one or more major life activities, as identified in the major classification systems such as the WHO International Classification of Diseases (ICD) and the Diagnostic and Statistical Manual of Mental Disorders (DSM)."9

<sup>8</sup> WHO. (2014). Mental health: a state of well-being. http://www.who.int/features/factfiles/mental\_health/en/

<sup>9</sup> Ibid

The WHO considers mental health a human right,<sup>10</sup> while the International Covenant on Economic, Social and Cultural Rights (ICESCR), to which South Africa is a state party, recognises the 'right of everyone to the enjoyment of the highest attainable standard of physical and mental health'.

# Approaches to understanding mental health

A number of models to understanding mental health have been described in the literature including the biomedical model, the biopsychosocial model and the social model. First, the biomedical approaches to mental health have traditionally been dominant and continue to prevail in most contexts. Biomedical approaches use the language of 'mental disorders' and consider the 'illness' as the primary focus of attention in dealing with mental health care users (MHCUs). Second, the biopsychosocial model recognises that medical and psychological conditions occur in a social, economic and political context. The biopsychosocial model emerged as a means to treat mental health conditions by focusing on the interacting components of biological pathologies as well as social and psychological determinants.<sup>11</sup> Finally, the social model considers 'impairment' as the product of an individual's interaction with their environment.<sup>12</sup> This is significant because it no longer views the individual as being pathologized or problematised, instead viewing the 'pathology' as the social environment that does not accommodate those with alternative abilities and needs. Psychosocial disability is a term used to describe the experience of people with participation restrictions related to mental health conditions, while intellectual disability is characterised by significant restrictions imposed on their participation in society because of differences in their intellectual functioning and abilities, and adaptive function and behaviour.<sup>13</sup>

The social model does not preclude the possibility of a biological or chemical determinant as a possible source of a mental health condition. Instead, it recognises that such a condition interacts with an environment that does not provide the necessary accommodations to support an individual to live as an equal member of society.

# The rights-based model, the CRPD and the Constitution

The rights-based model is strongly informed by the social model. It emphasises the equality of people with disabilities to all rights that apply to those without disabilities, including rights to participation, to autonomy and to inclusion in communities. Like the social model, it considers disability to be a product of an environment that fails to accommodate the specific needs of a person with a disability.<sup>14</sup>

The CRPD is an international human rights treaty, adopted by the United Nations in 2006. Parties to the Convention are required to promote, protect, and ensure the full enjoyment of human rights by persons with disabilities and ensure that they enjoy full equality under the law. The rights-based model is embodied by the CRPD and seeks to take into account diversity among people with disabilities, emphasising the universality of all rights and the inalienability of human dignity. South Africa signed the CRPD on the 30<sup>th</sup> of March, 2007 and ratified it eight months later. In terms of section 231(2) of the Constitution, this ratification renders the CRPD's provisions binding on the Republic.

The CRPD does not confer new rights on people with disabilities. Instead, it seeks to ensure that all rights applicable to people without disabilities are applied equally to the disabled. For the purposes of this report,

<sup>10</sup> Ibid.

Engel GL. (1977). The need for a new medical model: A challenge for medicine. Science, 196, 129.

<sup>&</sup>lt;sup>12</sup> Shakespeare T. (2002). The social model of disability: an outdated ideology? Research in Social Science and Disability, 2, 9.

South African Federation for Mental Health. (2017). What is Mental Health. http://safmh.org.za/index.php/who-we-are/what-we-do/what-is-mental-health

<sup>&</sup>lt;sup>14</sup> Amponsah-Bediako K. (2013). Relevance of disability models from the perspective of a developing country: An analysis. Developing country studies, 3, 11, 121.

United Nations Office of the High Commissioner for Human Rights. (2017). South Africa. http://tbinternet.ohchr.org/\_layouts/TreatyBodyExternal/Countries.aspx?CountryCode=ZAF&Lang=EN

a rights-based approach to mental health is one that is fully and completely compliant with the provisions of the Constitution and the CRPD. The CRPD's central guiding principles, which are pertinent in the context of an investigation into mental health, are articulated as on the following page:

# DIGNITY AND AUTONOMY

The Preamble to the Universal Declaration of Human Rights states that:

"Recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world"

Dignity being a universal and inalienable right, no condition or circumstance may be considered a justifiable infringement of it, including a mental health condition.

Section 1 of the Constitution states that South Africa is founded on the values of 'human dignity, the achievement of equality and the advancement of human rights and freedoms'. Similarly, the CRPD states its first guiding principle as:

"Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons"

Nobel-prize winning economist Amartya Sen argues that dignity is operationalised through the realisation of other tangible rights that allow one to thrive and to take full advantage of their capabilities. Therefore, a rights-based approach to mental health recognises that there is an intrinsic relationship between the right to health care and the right to dignity. The former (as enshrined in section 27 of the Constitution) facilitates the latter, and its progressive realisation must, therefore, intrinsically enhance the lived experience of the individual.

As per the CRPD, dignity incorporates both a recognition of the inherent, inalienable worth of people with psychosocial and intellectual disabilities and a recognition of their freedom to make choices regarding any matters that affect them. This latter right is elaborated upon in Article 12 of the CRPD on equal recognition before the law. The United Nations Committee on the Rights of Persons with Disabilities (the CRPD Committee) refers to legal capacity, in their General Comment on Article 12, as a universal human characteristic and advocates for people with psychosocial and intellectual disabilities to receive the necessary supports in order to make decisions under all circumstances.<sup>17</sup>

This paradigm reflects a significant shift from previous forms of decision-making with disability rights activists seeing it as a realisation of a previously much-abused right. Activist and legal scholar Tina Minkowitz, for example has argued that psychiatrists have often been perpetrators of violations of the right to freedom from torture or cruel, inhuman and degrading treatment (enshrined in section 12 of the Constitution and Article 15 of the CRPD) because of forced treatment of people with psychosocial and intellectual disabilities.<sup>18</sup> In contrast, this has been criticised in some quarters as irresponsible and regressive as it leaves people with

<sup>16</sup> Sen A. (2015). Universal Health Care: The Affordable Dream. Harvard Public Health Review, 4, 1.

<sup>&</sup>lt;sup>17</sup> CRPD Committee. (2014). General Comment 1 on Article 12 of the CRPD: Equal Recognition before the Law. UN Doc CRPD/C/GC/1.

Minkowitz T. (2007). The United Nations Convention on the Rights of Persons with Disabilities and the Right to be Free from Nonconsensual Psychiatric Interventions. Syracuse Journal of International and Comparative Law, 34, 405.

psychosocial and intellectual disabilities unprotected when they may be clinically unable to make decisions for themselves. Critics have included prominent officials from the South African Department of Health.<sup>19</sup>

The question of legal capacity for people with psychosocial and intellectual disabilities continues to be debated by scholars, clinicians and policy-makers. Both proponents and critics of universal legal capacity argue that a rights-based approach is best served by their position. There is therefore, not a clear and universally acceptable way forward on the subject of capacity for people with psychosocial and intellectual disabilities and this will require continued investigation, dialogue and potential reforms.<sup>20</sup> Importantly, this aspect of autonomy and legal capacity has the potential to affect numerous rights, including the right to political participation as contained in the Constitution (section 19) and the CRPD (Article 29), the right of access to justice (section 34 of the Constitution and Article 13 of the CRPD) and, as mentioned, the right to dignity and the right to freedom from torture, cruel, inhumane and degrading treatment. It is therefore, necessary that this debate be highlighted and acceptable solutions sought.

Dignity also means that people with psychosocial and intellectual disabilities are not passive recipients of charity, but active participants in their care and treatment. It is, therefore, essential, in seeking to realise a rights-based approach to mental health care, to consider mental health care users as equal partners.

## **EQUALITY AND NON-DISCRIMINATION**

International disability rights expert Gerard Quinn refers to equality and non-discrimination as the central guiding principle of the CRPD.<sup>21</sup> The equal enjoyment of all rights for people with disabilities is the primary objective of the Convention. As such, equality and non-discrimination affect all rights contained in the CRPD insofar as they should be enjoyed on an equal basis with others.

Article 5 of the CRPD also articulates explicitly the recognition that all people, including people with disabilities, are equal before and under the law, and requires state parties to the treaty to prohibit discrimination on the basis of disability. In South Africa, section 9 of the Constitution, includes disability as a prohibited ground for unfair discrimination. This is re-iterated by the Promotion of Equality and Prevention of Unfair Discrimination Act, No. 4 of 2000 (PEPUDA) and the Employment Equity Act, No. 55 of 1998 (EEA), as amended.

In respect of mental health, various forms of discrimination and stigma continue to impact negatively on the lives of people with psychosocial and intellectual disabilities. This is explored in detail below, but it is nonetheless worth noting the words of global mental health expert Norman Sartorius on the effect that stigma and discrimination can have on the mental health system:

# The stigma of mental illness and the consequent discrimination are the chief obstacles to the improvement of mental health care.<sup>22</sup>

A key principle of the CRPD, as contained in Article 3 of the Convention, is also equality between men and women, thus all rights that are enjoyed by men and boys with disabilities should be equally enjoyed by women and girls with disabilities.

<sup>&</sup>lt;sup>19</sup> Freeman MC et al. (2015). Reversing hard won victories in the name of human rights: A critique of the General Comment on Article 12 of the UN Convention on the Rights of Persons with Disabilities. Lancet Psychiatry, 2, 9, 844.

<sup>&</sup>lt;sup>20</sup> See, for example, Dhanda A. (2017). Conversations between the proponents of the new paradigm of legal capacity. International Journal of Law in Context, 13, 1, 87.

<sup>&</sup>lt;sup>21</sup> Quinn G. (2010). Personhood and Legal Capacity: Perspectives on the Paradigm Shift of Article 12 of the CRPD. http://www.nuigalway.ie/cdlp/documents/publications/Harvard%20Legal%20Capacity%20gq%20draft%202.doc

<sup>&</sup>lt;sup>22</sup> Cited in Sturgeon S. (2012). Stigma and Marginalisation: Structural Violence and the Impact on Mental Health. Social Work, 48, 58, 61.

# EFFECTIVE PARTICIPATION AND INCLUSION

Similar to equality, participation and inclusion are central principles of the CRPD and an important guiding value for how systems, including education and health care systems should approach the needs of people with disabilities. Article 3 of the CRPD lists 'effective participation and inclusion in society' as a general principle of the Convention.

Mental health is affected by the need for inclusion and participation in numerous ways. The slogan 'nothing about us without us' has been adopted by various user and survivor groups and the disability rights movement to articulate the need for a central role for people with disabilities themselves and for organisations that represent their interests.<sup>23</sup> Policies and laws developed without participation of people with psychosocial and intellectual disabilities, including through disabled peoples' organisations (DPOs), are inherently contrary to the rights-based approach.

Inclusion, while related to participation, also speaks to the right of people with disabilities to be integrated into their communities and societies to the fullest extent possible. This requires inclusive education and health care systems that adhere to Article 19 of the Convention on an equal basis with others. Inclusive education and health care systems do not segregate or confine people with psychosocial and intellectual disabilities, instead seeking to integrate them into community-based service models and into 'mainstream' facilities to the fullest extent possible.

Deinstitutionalisation from residential psychiatric facilities to community-based services that allow people with psychosocial and intellectual disabilities to live independently and enjoy fully all rights on an equal basis as others is, therefore, a central component of a rights-based approach to mental health, although this ought to be done in a manner that is mindful of the dignity of those being deinstitutionalised.<sup>24</sup>

Research has demonstrated that efforts to promote participation in society through the provision of work opportunities and training can also be useful psychosocial support interventions in addition to traditional mental health care services.<sup>25</sup> A rights-based approach to mental health recognises that addressing social and economic barriers to participation is a fundamental aspect of service provision. Considering that people with psychosocial and intellectual disabilities are more likely to be affected by poverty, unemployment and a lack of opportunities than the general population,<sup>26</sup> addressing these determinants of mental health should be considered central to the realisation of effective participation and inclusion.

# RESPECT FOR DIFFERENCE AND ACCEPTANCE OF PERSONS WITH DISABILITIES AS PART OF HUMAN DIVERSITY AND HUMANITY

A rights-based approach to mental health recognises and respects diversity both between persons with psychosocial and intellectual disabilities and broader society and within the group of people with psychosocial and intellectual disabilities. This requires an approach that is aware and respectful of cultural differences that might affect the manner in which mental health is viewed and the manner in which mental health care is delivered. Article 30 of the CRPD and sections 30 and 31 of the Constitution also articulate the right to participate in a cultural, linguistic and religious life of one's choosing. As such, mental health care that is grounded in a human rights-based approach should be critically aware of these differences, be appreciative

<sup>&</sup>lt;sup>23</sup> Charlton Jl. (1998). Nothing about us without us: Disability Oppression and Empowerment.

<sup>&</sup>lt;sup>24</sup> Jenkins et al. (2011). Social, economic, human rights and political challenges to global mental health. Mental Health in Family Medicine, 8, 2, 87.

Boardman et al. (2003). Work and employment for people with psychiatric disabilities. The British Journal of Psychiatry, 182, 6.

Perkins R & Rinaldi M. (2002). Unemployment rates among patients with long-term mental health problems: A decade of rising unemployment. BJPsych Bulletin, 26, 8, 295; Murali V & Oyebode F. (2004). Poverty, social inequality and mental health. Advances in Psychiatric Treatment, 10, 3, 216.

of these differences and offer services that take these contextual, social, cultural and linguistic differences into account.<sup>27</sup>

Similarly, respect for difference and diversity among people with psychosocial and intellectual disabilities requires a recognition that supports which may be suitable for one individual may not be adequate for another. Therefore, a human rights-based approach to mental health care is, by definition, person-focused and requires an evaluation of an individual's specific needs.

# **EQUALITY OF OPPORTUNITY**

Equality of opportunity refers to the accommodations and supports provided to people with disabilities to engage with society as full and equal members, while also addressing barriers to opportunities, including lack of resources and capacity. As such, equality of opportunity requires that workplaces ensure reasonable accommodation for people with psychosocial and intellectual disabilities. Similarly, it requires that the state afford the same opportunities for education and health care as people without disabilities. This suggests a substantial allocation of resources as well as clear political will to manifest.<sup>28</sup>

# **ACCESSIBILITY**

An accessible environment is, by definition, required for people with psychosocial and intellectual disabilities to fully exercise their rights. A rights-based approach will require that accessibility concerns are taken into account and that persons who require services such as education and health care are able to access them, including but not limited to psychotropic treatment. This means both physical as well as material and economic accessibility, suggesting that reforms include both changes that make the physical and built environment disability-friendly (including accommodations for sign language), as well as resourcing to ensure that those who require services can access them in a manner that is not onerous or unreasonable. Importantly, this, too requires some consideration as to how the private sector can contribute to ensuring accessibility of mental health care, among other basic services.<sup>29</sup>

# RESPECT FOR THE EVOLVING CAPACITIES OF CHILDREN WITH DISABILITIES AND RESPECT FOR THE RIGHT OF CHILDREN WITH DISABILITIES TO PRESERVE THEIR IDENTITIES

Mental health care for children has historically adopted an approach that does not take into account the evolving capacities of children with disabilities and the concomitant need to adapt and tailor services to take these evolving capacities into account.<sup>30</sup> In keeping with the person-focused orientation of a human rights-based approach to mental health, this should shift to adequately meet the needs of children with psychosocial and intellectual disabilities.

Section 28(2) of the Constitution and Article 7 of the CRPD note that the best interests of the child should be of paramount concern in all matters concerning the child. This, then, includes a consideration of what supports and adaptations are required to realise mental health services that are concordant with the best interests of that specific child. Section 28(1) (c) of the Constitution also makes specific mention of the right

<sup>&</sup>lt;sup>27</sup> Read UM et al. (2009). Local suffering and the global discourse of mental health and human rights: An ethnographic study of responses to mental illness in rural Ghana. Globalization and Health, 5, 13.

Saraceno B et al. (2007). Barriers to improvement of mental health services in low-income and middle-income countries. Lancet, 370, 9593, 1164.

<sup>&</sup>lt;sup>29</sup> Ward T & Stewart C. (2008). Putting Human Rights into Practice with People with an Intellectual Disability. 20, 3, 297.

<sup>&</sup>lt;sup>30</sup> Brown SE & Guralnick MJ. (2012). International human rights to Early Intervention for Infants and Young Children with Disabilities: Tools for Global Advocacy. Infants and Young Children, 25, 4, 270.

to basic health care services for children, while section 28(1) (f) (ii) requires that children should be protected from work or the performance of services that 'place at risk the child's well-being, education, physical or mental health'.

There is therefore, substantial guidance already as to what constitutes a rights-based approach to mental health care. Even so, the hearing highlighted considerable gaps between the manner in which mental health care is conceived of and provided in South Africa, and the normative and conceptual understanding of a rights-based approach.



# 3. MENTAL HEALTH IN THE SOUTH AFRICAN CONTEXT

# The legal and policy framework

# International Covenant on Economic, Social and Cultural Rights (ICESCR) and General Comment 14

outh Africa ratified this Covenant in 2016. As mentioned, the ICESCR recognises the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. Considering that a stated component of the 'minimum core' standard of the Right to Health, as determined by the International Committee on Economic, Social and Cultural Rights (CESCR), is non-discrimination,<sup>31</sup> any systematic marginalisation, by commission or omission, of people with psychosocial and intellectual disabilities (including in the health care system) may potentially be a violation of the Right to the Highest Attainable Standard of Health, as contained in the ICESCR. Importantly, the 'minimum core' of the right to health also includes special consideration of the needs of those considered 'most vulnerable', a group that includes persons with disabilities. Therefore, while progressive realisation of a right is, in and of itself, a rational approach, it cannot be used to shield the state from failing to meet the needs of the country's most 'vulnerable' individuals.

The 'minimum core' standard has been eschewed in South African jurisprudence, with the Constitutional Court preferring a 'reasonableness' test to assess whether the state is meeting its commitments in respect of economic, social and cultural rights. However, the Court's deliberation of this issue in *Minister of Health v Treatment Action Campaign* is instructive. Yacoob J states that 'there may be cases where it may be possible and appropriate to have regard to the content of a minimum core obligation to determine whether the measures taken by the [s]tate are reasonable'. More pointedly, the avoidance of the 'minimum core' standard does not detract from the fact that the state is required, even under a 'reasonableness' review, to pay attention to issues of inclusivity and to the specific needs of vulnerable populations. In *Government of the Republic of South Africa v Grootboom*, Yacoob J notes that '[a] programme that excludes a significant segment of society cannot be said to be reasonable'. He goes on to state that:

"[T]hose whose needs are the most urgent and whose ability to enjoy all rights therefore is most in peril, must not be ignored by the measures aimed at achieving the realisation of the right"

The application of any standard therefore requires that health care policy does not discriminate, particularly insofar as the rights and needs of those most susceptible to marginalisation are concerned.

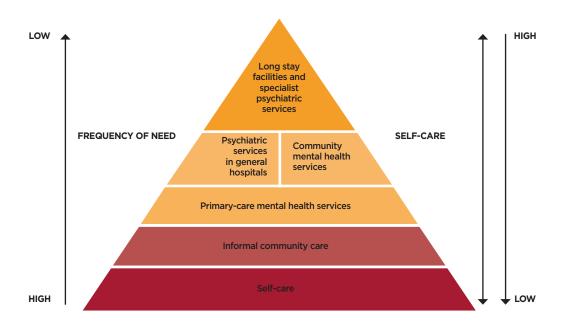
<sup>&</sup>lt;sup>31</sup> Committee on Economic, Social and Cultural Rights. (2000). General Comment 14. The right to the highest attainable standard of health. U.N. Doc. HRI/GEN/1/Rev.6.

# World Health Organisation (WHO) Pyramid Framework, Mental Health Gap Action Programme (mhGAP) and the Quality Rights initiative

The WHO has developed several sources of normative guidance relating to best practice in the provision of public mental health services. The Mental Health Policy and Service Guidance package was developed to assist countries to optimise their mental health services to meet the needs of their populations, recognising that limited resources and increasing levels of mental health challenges were being identified.<sup>32</sup> The Pyramid Framework was introduced as a general guidance for national health ministries to engage in the provision of cost-effective and need-appropriate mental health services. The framework highlights the need for self-care as the 'base of the pyramid', requiring states to facilitate self-care as a first-line intervention to address mental health needs. Informal community care and the provision of mental health care in primary health settings are also supported as less costly and more efficacious interventions. Specialised mental health treatment in community settings and generalist hospitals are seen as less costly and more widely utilised than specialised services in dedicated mental health settings, including long-stay facilities.<sup>33</sup>

Countries are urged to optimise mental health care by following the Pyramid Framework, particularly low and middle-income countries whose resources are limited, thus avoiding unnecessary spending on costly infrastructure for long-stay institutions. The WHO notes that no country has been able to fully optimise its services to meet this model, but suggests that there are possibilities for creating agency, developing peer support mechanisms and improving the interface between physical and mental health.<sup>34</sup>

Figure 1: WHO Optimal Mix of Services



QUANTITY OF SERVICES NEEDED

World Health Organization. (2003). Organization of services for mental health. http://www.who.int/mental\_health/policy/services/4\_organisation%20services\_WEB\_07.pdf?ua=1

World Health Organization. (2007). The optimal mix of services for mental health. http://www.who.int/mental\_health/policy/services/2\_Optimal%20Mix%20of%20Services\_Infosheet.pdf

World Health Organisation. (2003). As above.

Recognising that a significant gap exists between people who need mental health services and people who are able to access them, particularly in low and middle-income countries, the WHO launched the mhGAP programme in 2002.<sup>35</sup> The primary emphasis of mhGAP is scalability of interventions in contexts where resources are scarce. It focuses on both prevention and treatment of 'priority conditions'. Among the criteria for selecting these priority conditions were the prevalence of the condition, the economic cost of the condition and the propensity for human rights violations associated with the condition. The mhGAP therefore, primarily addresses depression, schizophrenia and other psychotic disorders, suicide, epilepsy, dementia, disorders due to use of alcohol, disorders due to use of drugs and mental disorders in children. The four core strategies identified by the programme were information, policy and service development, advocacy, and research.<sup>36</sup>

The mhGAP has since supported interventions in the area of establishing core principles to guide interventions, developing policy, supporting research relating to implementation and capacity-building to ensure that mental health services can be provided in primary care settings. mhGAP was integrated into some clinical protocols in South Africa, and, like the Pyramid Framework, has been influential in shifting the emphasis from specialised care in institutional settings to the provision of mental health care services in primary care settings. Interventions have been carried out in South Africa using mhGAP guidelines by organisations such as the Programme for Improving Mental Health (PRIME).<sup>37</sup> Following a review of the evidence base supporting mhGAP-related interventions, a second edition of the mhGAP intervention guide was launched in 2016.<sup>38</sup>

The Quality Rights project of the WHO was launched in recognition of the fact that human rights violations have been commonplace in traditional mental health settings and that this contributes to further ill-health as well.<sup>39</sup> The initiative is intended to provide a standardised 'toolkit' for ensuring that human rights norms and standards, informed by the CRPD, are adhered to in all mental health settings. In addition to the monitoring and standardisation of services, the initiative seeks to ensure that laws and policies are harmonised with norms and standards, including the CRPD and to provide technical assistance to states who are undertaking such reforms. Similarly, it aims to support the participation of people with psychosocial disabilities in the process of policy-making and service provision and to build a movement of people with psychosocial disabilities that advocate effectively for their own rights.<sup>40</sup> The Quality Rights toolkit has not yet been applied in South Africa.

# Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa<sup>41</sup>

This Protocol was adopted in January 2018. The protocol guarantees equal protection of economic, social, cultural, civil, and political rights to individuals with 'physical, mental, intellectual, developmental or sensory impairments' and requires States parties to implement affirmative actions to advance their equality. This includes an obligation, incumbent upon signatories, to ensure that the training of health-care providers takes account of the disability specific needs and rights of persons with disabilities.<sup>42</sup>

World Health Organisation. (2008). mhGAP: Mental Health Gap Action Programme: scaling up care for mental, neurological and substance use disorders. http://apps.who.int/iris/bitstream/handle/10665/43809/9789241596206\_eng.pdf?sequence=1

<sup>36</sup> Ibid.

Lund C et al. (2012). Mental Health Services in South Africa: Taking stock. African Journal of Psychiatry, 15, 402; Mental Health Innovation Network. (undated). PRIME. http://www.mhinnovation.net/innovations/prime-programme-improving-mental-health-care

World Health Organisation. (2016). MhGAP intervention guide 2.0. http://apps.who.int/iris/bitstream/hand le/10665/250239/9789241549790-eng.pdf?sequence=1

<sup>&</sup>lt;sup>39</sup> World Health Organisation. (2012). Quality Rights Toolkit. http://apps.who.int/iris/bitstreamhandle/10665/70927/9789241548410\_eng.pdf?sequence=3

<sup>40</sup> Ibid.

<sup>&</sup>lt;sup>41</sup> Draft Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa. http://www.achpr.org/files/news/2016/04/d216/disability\_protocol.pdf

<sup>&</sup>lt;sup>42</sup> Article 13(i)

### Purohit and Another v Gambia<sup>43</sup>

This is the sole disability-related decision rendered by the African Commission for Human and Peoples' Rights (African Commission). In this matter, the Commission recognised that the right to appeal involuntary detention was essential for the assurance of the dignity of persons with psychosocial disabilities, while also asserting that laws which inadequately protected the rights of these persons constituted a failure to recognise their special needs and, therefore, amounted to discrimination.<sup>44</sup>

The judgment also asserted the centrality of respect for the freedom of movement and association of people with psychosocial and intellectual disabilities, while encouraging states 'to take concrete and targeted steps, while taking full advantage of its available resources, to ensure that the right to health is fully realised in all its aspects without discrimination of any kind'.<sup>45</sup> Legal scholar Mawuse Anyidoho interprets this to mean that mental health should comprise a significant proportion of the health budget, and that the failure to do so constitutes discrimination against those affected by psychosocial and intellectual disability.<sup>46</sup>

# Mental Health Care Act, No. 17 of 2002 and the Mental Health Care Regulations, 2003

When introduced, South Africa's Mental Health Care Act (the MHCA) was considered one of the most progressive pieces of mental health legislation in the world. The Act explicitly affirms the rights of all people under its ambit, and significantly limits the potential for substitute decision-making and involuntary treatment. The Act does contain provisions which allow for a finite confinement of 72 hours to establish the need for involuntary treatment in some cases. It also allows for an individual to be declared 'of unsound mind' by the High Court. These provisions are in tension with the CRPD's emphasis on supported decision-making, and directly contradict the General Comment on Article 12 (a non-binding instrument). Other avenues for supported decision-making such as the issuance of advance directives, are not provided for in the MHCA.

The MHCA also introduced Mental Health Review Boards (MHRBs), which are intended to serve as bodies that monitor the observance of human rights in mental health facilities. According to the MHCA, these bodies, appointed in each district by members of the executive council (MECs) for health in the provinces, are independent oversight mechanisms for MHCUs to approach in the event that they wish to contest their institutionalisation and, along with the designated head of the health establishment (HHE), are the primary decision-making bodies with regard to involuntary and assisted treatment of MHCUs. While the MHRBs have been lauded as potentially useful mechanisms for seeking recourse, these bodies have been shown to be dysfunctional in numerous instances, because of the unavailability of board members, because of poor resourcing to facilitate their work or because of vacancies.<sup>47</sup>

As with other pieces of legislation, the MHCA was supplemented by regulations pertaining to its implementation in 2003. These regulations contain various provisions regarding how processes such as transfer and discharge are conducted, the role of national and provincial governments in respect of developing quality norms and standards and the regulation of facilities. Regulation 48 stipulates that provincial departments of health are responsible for issuance of licenses to NGOs and CBOs that facilitate the care of people with psychosocial and intellectual disabilities. It is notable that Regulation 6, which obliged the State to subsidise NGO-run residential homes and day care centres, was amended in 2014 to include the words "[w]ithin available resources".<sup>48</sup>

<sup>&</sup>lt;sup>43</sup> (2003) AHRLR 96 (ACHPR 2003).

<sup>&</sup>lt;sup>44</sup> Ibid, paras 53-57.

<sup>&</sup>lt;sup>45</sup> Ibid, para 84.

<sup>&</sup>lt;sup>46</sup> Anyidoho M. (2004). The right to health for mental health patients: African Commission. Housing and ESC Rights Quarterly 1, 4.

<sup>&</sup>lt;sup>47</sup> Bateman C (2012). Dismal use of legal safety net for mental health patients. South African Medical Journal, 102, 2.

<sup>&</sup>lt;sup>48</sup> Regulation 6. General Regulations Relating to the Mental Health Care Act, 2002: Amendment. 6 November 2014.

### Electoral Act, No. 34 of 2003 (as amended)

Section 8(c) of the Electoral Act states that a person declared by the High Court to be 'of unsound mind' cannot be placed on the voters' roll, regardless of when such a declaration was made, while section 8(d) states that anyone detained under the MHCA may not be placed on the voters' roll. These provisions have been criticised as being non-compliant with the CRPD's position on legal capacity, while also unduly denying people with psychosocial and intellectual disabilities the right to political participation as protected under the Constitution and the CRPD.<sup>49</sup> Representatives of people with psychosocial and intellectual disabilities have sought to change these provisions through legislative means, but, to date, amendments to the Act have not done so.<sup>50</sup> The South African Federation for Mental Health (SAFMH) reported that, on 29 June 2018, Parliament was briefed on possible legislative reforms to the Electoral Act which will allow MHCUs to vote in elections.<sup>51</sup> There have, thus far, not been legal proceedings to challenge the validity of these provisions, although the Commission has, in the past, been approached for assistance in doing so.

### The National Health Act and National Health Insurance

South Africa's National Health Act, No. 61 of 2003 (NHA) was 'designed to unify the manner in which the various components of the national health system operate so as to provide for equitable, efficient and internationally recognised standardised healthcare to all South Africans'.<sup>52</sup> Among its provisions are the creation of various categories 'of persons eligible for free health services at public health establishments' and section 5 mandates a health care provider, health worker or health establishment to provide any person who requires it with emergency medical treatment.<sup>53</sup> Section 36(1) of the NHA prohibits anyone from operating a health establishment with effect from twenty-four months from the date on which chapter 6 becomes effective without a 'certificate of need'. This controversial provision has not yet been activated as chapter 6 of the NHA has not yet become effective. The NHA also introduces the principle of informed consent for medical treatment and strengthens rights to privacy and confidentiality of health care users.<sup>54</sup>

While the NHA regulates the practice of health care and focuses on expanding access to quality health care, the National Health Insurance (NHI) scheme is intended to operationalise the financial means for people to do so. Guided by the provisions of section 27 of the Constitution, the NHI is intended to achieve the goal of universal health coverage (UHC) in South Africa by creating a pooled fund to 'provide access to quality, affordable personal health services for all South Africans based on their health needs, irrespective of their socioeconomic status', essentially bridging the gap in South Africa's two-tiered health care system.<sup>55</sup>

NHI has been a controversial subject as well, particularly among private health care providers who will be required to participate and among economists who doubt whether the country can sustain the costs of UHC.<sup>56</sup> At present, the NHI is being piloted in 11 districts across the country, where 'comprehensive health services' are being provided to cater not only for the treatment of illnesses but, also for the prevention of further challenges. According to reports, challenges have been encountered with regard to building confidence in

<sup>&</sup>lt;sup>49</sup> Parliamentary Monitoring Group. (2013). Electoral Amendment Bill [B22-2013]: Public Hearings. https://pmg.org.za/committee-meeting/16327/

<sup>50</sup> Ibid.

<sup>51</sup> http://www.safmh.org.za/index.php/news/item/175-mental-health-care-users-and-the-right-to-vote

 $<sup>^{52}\,\,</sup>$  Preamble of the National Health Act, No. 61 of 2003.

<sup>&</sup>lt;sup>53</sup> Kirby N. (2005). South Africa: The National Health Act: A guide for beginners. http://www.mondaq.com/southafrica/x/32307/Healthcare/The+National+Health+Act+A+Guide+For+Beginners

<sup>54</sup> Ibid.

Department of Health. (2015). National Health Insurance for South Africa. https://www.health-e.org.za/wp-content/uploads/2015/12/National-Health-Insurance-for-South-Africa-White-Paper.pdf

Settas M. (2017). Health Policy shambles. https://www.mm3admin.co.za/documents/docmanager/f447b607-3c8f-4eb7-8da4-11bca747079f/00126798.pdf

the public health care system, corruption and maladministration, staff recruitment and retention and the adequacy of facilities.<sup>57</sup>

NHI includes mental health as part of the package of 'comprehensive health services'. The NDOH has targeted 2026 for the full implementation of the NHI scheme. The second National Health Insurance White Paper was introduced in 2017<sup>58</sup> and, in his State of the Nation address on the 16<sup>th</sup> of February, 2018, the President of the Republic of South Africa also noted that a bill to finalise the rollout of the NHI would be introduced in Parliament within the current legislative cycle.<sup>59</sup> It is a concern that the 2017 National Health Insurance White Paper does not currently make allowance for community-based care of MHCUs. This appears to be inconsistent with the NHMPF, which refers to norms and standards for psychiatrists, psychologists, psychiatric nurses and allied professionals developed for community-based mental health care services.<sup>60</sup>

# De Vos N.O. and Others v Minister of Justice and Constitutional Development and Others<sup>61</sup>

This matter is the only case dealing with the rights of people with psychosocial and intellectual disabilities at the level of the Constitutional Court of South Africa. The Court held that it was an unconstitutional infringement on the rights of such persons to detain them in a prison while awaiting trial if the presiding officer was unsure of their competence to stand trial. The Court affirmed the right to dignity of people with psychosocial and intellectual disabilities, and also noted the significant stigma that they face in society. Leeuw AJ states the following:

Accused persons with mental illnesses or intellectual disabilities have been historically disadvantaged and unfairly discriminated against...The right to dignity is not only a basic tenet of our Constitution; it is a value that is central to the interpretation of the section 12 right to freedom and security of the person... Imprisonment reinforces the stigma and marginalisation that people, like the accused in this matter, are subjected to on a routine basis. This impairs the human dignity of persons with mental illnesses or intellectual disabilities.<sup>62</sup>

The Court finds that the appropriate remedy is to treat an accused person with a psychosocial or intellectual disability as an involuntary patient under the MHCA. While it is clear that the Court's affirmation regarding the rights to dignity and freedom and security of the person are considerable strides, the question of legal capacity as a universal characteristic, as per the CRPD's position, has not been tested in the Court.

<sup>&</sup>lt;sup>57</sup> Amado L et al. (2012). National Health Insurance: A lofty ideal in need of cautious, planned implementation. South African Journal of Bioethics and Law, 5, 1, 4.

National Health Insurance. (2017). National Health Insurance White Paper. http://www.mm3admin.co.za/documents/docmanager/f447b607-3c8f-4eb7-8da4-11bca747079f/00124581.pdf

<sup>&</sup>lt;sup>59</sup> Ramaphosa C. (2018). State of the Nation Address by the President of the Republic of South Africa. http://www.zimeye.com/2018/02/16/full-text-ramaphosa-sona-speech-which-made-south-africa-cry/

National Health Insurance. (2017). National Health Insurance White Paper. http://www.mm3admin.co.za/documents/docmanager/f447b607-3c8f-4eb7-8da4-11bca747079f/00124581.pdf

<sup>&</sup>lt;sup>61</sup> 2015 (2) SACR 217 (CC).

<sup>62</sup> Ibid, para 46.

### National Mental Health Policy Framework and Strategic Plan 2013-2020 (NMHPF)<sup>63</sup>

The NMHPF is South Africa's first officially endorsed national mental health policy, with the country previously having relied on instruments such as White Papers to inform policy choices. The policy considers mental health to be an integral part of 'general health care'. The objectives of the NMHPF are as follows:

- a. To scale up decentralised integrated primary mental health services, which include community-based care, PHC clinic care, and district hospital level care;
- b. To increase public awareness regarding mental health and reduce stigma and discrimination associated with mental illness;
- c. To promote the mental health of the South African population, through collaboration between the Department of Health and other sectors;
- d. To empower local communities, especially mental health service users and carers, to participate in promoting mental wellbeing and recovery within their community;
- e. To promote and protect the human rights of people with mental illness;
- f. To adopt a multi-sectoral approach to tackling the vicious cycle of poverty and mental ill-health;
- g. To establish a monitoring and evaluation system for mental health care; and
- h. To ensure that the planning and provision of mental health services is evidence-based.

The policy places specific emphasis on the participation of people with psychosocial and intellectual disabilities and social supports in addition to psychiatric services. The policy also states that mental health parity (i.e. equal provision for mental health and physical health) should be treated as a priority in the future implementation of the National Health Insurance (NHI) and that private medical schemes should be required to apply a similar parity principle.

The NMHPF states that the responsibility for development of the policy and legislation as well as monitoring of their implementation are the responsibilities of the Minister of Health. Similarly, the promotion of mental health awareness and the realisation of equitable service provision between provinces are also the responsibility of the National Department. The Minister is assisted by the Ministerial Technical Advisory Committee on Mental Health, made up of clinicians, policy-makers, representatives from DPOs and academia. The Director-General's office is responsible for the development of a national strategic plan and for development of strategies relating to norms and standards and human resource capacity.

Provinces are responsible for the development of a provincial strategic plan and the establishment of Mental Health Directorates. Importantly, provincial departments of health are also responsible for the 'Provision of a sustainable budget for mental health services, keeping parity with other health conditions, in proportion to the burden of disease, and evidence for cost-effectiveness' and for expanding the mental health workforce, in accordance with national strategies. As with all health care services, the 52 districts, in consultation with provincial departments, are responsible for service provision in community-based and hospital settings, including psychotherapy and medication. Districts are also responsible for carrying out education initiatives in communities and for training and supervision of local staff, through the establishment of District Mental Health Teams (DMHTs). To enhance participation of people with psychosocial and intellectual disabilities in their communities and in decisions relating to mental health care, in accordance with the provisions of the CRPD, the NMHPF also calls for the establishment of mental health stakeholder forums.

In principle, the NMHPF has been lauded as a significant step forward in the mental health care landscape in South Africa. In practice, however, progress has been inconsistent and implementation has been challenging. In reference to the stigma-reduction initiatives envisioned by the policy, a 2015 study states:

Department of Health. (2013). National Mental Health Policy Framework and Strategic Plan 2013-2020. https://www.health-e.org.za/wp-content/uploads/2014/10/National-Mental-Health-Policy-Framework-and-Strategic-Plan-2013-2020.pdf

"The mental health policy framework does not provide sufficient guidance on how stigma should be addressed, with provincial and district level respondents not being aware of any specific antistigma programmes for mental health and variations between provinces in terms of prioritising addressing stigma." 64

National-level monitoring is seeking to assess implementation, and while there has been a published national strategic plan, numerous provincial strategic plans have yet to be finalised, and mental health directorates in these provinces have not yet been established. Mental health parity in private health schemes is non-existent and, while some conditions such as 'major depression' are included in the Prescribed Minimum Benefits (PMB) standard for medical schemes, there remains a significant gap in comprehensive coverage. <sup>65</sup> Chapter 6 of this report, detailing submissions from the National and Provincial Departments of Health to the Commission's hearing, examines the monitoring of implementation of the NMHPF in greater detail.

# **Policy on Adult Primary Care (APC)**

This policy is currently being rolled out throughout the country's primary health care (PHC) facilities. The aim is to provide 'integrated care' for health care users within the PHC system. It therefore, requires that health care workers within the PHC system are familiar with symptomatology as well as basic treatment options. The policy contains specific guidelines for PHC workers who encounter people with psychosocial or intellectual disabilities, and provides guidance on basic measures applicable to a PHC context.<sup>66</sup>

# **National Disability Rights Policy (NDRP)**

In December 2015, Cabinet approved a White Paper on the Rights of Persons with Disabilities, with the explicit intention of incorporating provisions of the CRPD into national frameworks.<sup>67</sup> The White Paper, also known as the National Disability Rights Policy, contains provisions related to the 'mainstreaming' of disability into all areas of public and private life. Particular emphasis is also placed on a rights-based approach to disability, with provisions for the protection as well as the promotion of the rights of people with disabilities. In addition, Cabinet also approved a set of targets for the period 2015-2030. This 'implementation matrix' contains measures of compliance, with the first set of targets having a deadline of 2019.<sup>68</sup>

A progress report on the implementation of the NDRP highlighted some key challenges that impede the ability of people with disabilities to access their rights on an equal basis with others, including capacity challenges and a lack of accurate data to inform programming.<sup>69</sup> Another significant barrier noted was the lack of interdepartmental coordination and the need for departments other than the DSD to drive forward progress on this policy. An increase in school enrolment among children with disabilities was noted, but without accurate data, it remains unclear how many children and adolescents were not receiving an education.<sup>70</sup> Lack of

Marais DL & Petersen I. (2015). Health system governance to support integrated mental health care in South Africa: Challenges and opportunities. International Journal of Mental Health Systems, 9, 1.

Independent Financial Consultants. (2017). Medical Aid Schemes That Cover Psychotherapy. https://www.medicalaid-quotes.co.za/articles/medical-aid-schemes-cover-psychotherapy. The Commission notes that, in this context, PMBs cover acute hospitalisation only. Where depression is the diagnosis, outpatient psychotherapy is covered but not maintenance treatment with antidepressants. Further, maintenance treatment of schizophrenia is not included as a PMB, only acute hospital care. This arguably places individuals diagnosed with schizophrenia at a higher risk of relapse.

National Department of Health. (2017). Adult Primary Care. http://www.up.ac.za/media/shared/62/ZP\_Files/adult-primary-care-manual-2016-formally-primary-care-101-.zp106384.pdf

Department of Social Development. (2015). White Paper on the Rights of Persons with Disabilities. http://www.dsd.gov.za/index.php?option=com\_docman&task=doc\_download&gid=653&Itemid=39

Department of Social Development. (2015). Implementation Matrix for the WPRPD. http://www.dsd.gov.za/index.php?option=com\_docman&task=doc\_download&gid=654&Itemid=39

<sup>&</sup>lt;sup>69</sup> Department of Social Development. (2016). First Annual Progress Report on the Implementation of the White Paper on the Rights of Persons with Disabilities.

<sup>&</sup>lt;sup>70</sup> Ibid.

accountability and redress mechanisms was highlighted as a considerable obstacle to implementation, and the need for increased support of civil society actors was noted.<sup>71</sup>

## Policy on the Provision of Social Development Services to Persons with Disabilities

This policy, adopted in 2017 by the National DSD, was developed to ensure that services for people with disabilities would be standardised and aligned with the NDRP across the country. It was also crafted to 'mainstream' disability throughout the work of all departments and institutions of the state. Several 'micropolicies' are contained under this framework, including:

- The Policy on Residential Facilities for Persons with disabilities;
- The Policy on Protective workshops;
- The Policy guidelines on Respite Care services;
- The National Strategy towards Integrated services to children with disabilities;
- · Registration guidelines for Residential facilities;
- Minimum standards for Residential facilities;
- The Psychosocial Support programme for Protective workshops; and
- The Disability Mainstreaming toolkit

Provincial DSD's are responsible for the implementation of these principles. The policy requires that services for supported decision-making are developed as is a community-based system for personal assistance to support independent living within the community for persons with disabilities. It also provides for financial support to be directed towards DPOs to strengthen advocacy and outreach efforts relating to the advancement of the rights of people with disabilities. Further, it contemplates the development of indicators for measuring progress on implementation, and the establishment of governance structures, including national, provincial and local disability multi-stakeholder fora. Inter-sectoral collaboration between DSD was highlighted as an important contributor to success, and the Minister of Social Development is tasked with engaging peer ministers on subjects such as the application of NHI to people with disabilities, the provision of appropriate interventions to children and adolescents with disabilities in schools. The policy does make mention of the rights of people with disabilities to live in their communities and undertakes to provide the necessary supports to do so. However, it does not engage with the subject of how DSD envisions its own role insofar as deinstitutionalisation is concerned.

### **Policy on Residential Facilities for Persons with Disabilities**

This policy of the National DSD aims to standardise the services provided by the Department in relation to residential facilities for adults and children with disabilities. It also aims to specifically address governance and capacity issues, identified as potential impediments to quality supports. The policy stipulates that all residential facilities must adhere to the CRPD's principles, including the right to an adequate standard of living and social protection. It further recognises that, in accordance with Article 19 of the CRPD, governments should take steps to promote independent living and to provide appropriate supports for this wherever possible. Nonetheless, it makes provision for residential care and support where independent living may not be possible.

The policy is accompanied by a set of norms and standards which facilities are required to adhere to in order to be registered, encompassing safety and physical standards as well as care and support standards. The participation of people with disabilities in the governance of these facilities is also provided for through the institution of resident committees. Inter-departmental collaboration is mandated, with the DOH responsible

for provision of services to people with 'mental illness'. The implementation of this policy is intended to be subject to continuous monitoring and evaluation.

## Infrastructure Unit Support Systems Project (IUSS) Mental Health Facilities Guidelines

Published in 2014, these guidelines provide direction regarding the physical environment in which mental health care services are to be rendered. It lists various norms and standards to which all mental health care facilities, at primary, secondary and tertiary levels, must adhere. This includes features such as security and accessibility features. The guidelines also explicitly recognise that the physical environment in which MHCUs find themselves must be conducive to the realisation of their human rights. Therefore, a built environment that is not accessible to people with disabilities or that might be considered a violation of the right to freedom from cruel, inhuman and degrading treatment cannot reasonably be said to adhere to these guidelines.

# Prevalence statistics and data concerns<sup>72</sup>

The first nationally representative survey of prevalence of mental health conditions among adults was conducted between 2003 and 2004, with a particular a focus on common mental disorders (CMDs), including depression, anxiety and substance use disorders. The South African Stress and Health (SASH) study was conducted as part of the WHO's World Mental Health Survey Initiative.<sup>73</sup> The study refers to 'relatively high' prevalence rates of mental health conditions, finding that the lifetime prevalence for any mental health condition in South Africa was 30.3%. Anxiety disorders were the most prevalent form of 'disorder', while substance abuse and 'mood disorders' were the next most prevalent conditions in South Africa. The study also noted differences in prevalence across provinces, noting that the Western Cape and the Free State had significantly higher prevalence of mental health conditions than other parts of the country, while the Eastern Cape and the Northern Cape had prevalence figures that were significantly lower than the rest of the country.<sup>74</sup> It is however notable that the General Household Survey of 2017 indicated that the Eastern Cape had the highest prevalence of 'mental illness' followed by Gauteng and KwaZulu-Natal.<sup>75</sup>

Prevalence statistics relating to psychosocial and intellectual disabilities are often under-estimates. There are a number of reason for this, including, the SASH study only focusing on CMDs and not severe mental disorders such as schizophrenia and bipolar disorder; the stigma associated with reporting mental health problems; and because of a lack of sufficient skilled personnel to accurately diagnose potential challenges. Apart from the SASH study, smaller studies have also demonstrated high prevalence of mental health conditions in South Africa, exhibited in one study by attempted suicide rates of 7.8% and rates of suicidal ideation of 19% among high school students. Another study found a 22% prevalence rate of post-traumatic stress disorder (PTSD) among South African school children. Post-partum depression rates as high as 34.7% have been documented, as have rates as high as 37% for depression. These findings illustrate that South Africans

The data presented under this heading relates primarily to mental health conditions which are distinguishable from intellectual disabilities which may or may not be accompanied by mental health conditions. Certain conclusions regarding the prevalence of intellectual disability in South Africa can be drawn from the Census 2011 data although intellectual disability was not measured directly. For more information see 'Profile of persons with disabilities in South Africa' available at: http://www.statssa.gov.za/publications/Report-03-01-59/Report-03-01-592011.pdf.

Herman AA et al. (2009). The South African Stress and Health (SASH) study: 12-month and lifetime prevalence of common mental disorders. South African Journal of Medicine, 99, 5, 2, 339.

<sup>74</sup> Ibid.

<sup>75</sup> Statistics South Africa. (2017). General Household Survey: 2017. Available at: http://www.statssa.gov.za/publications/P0318/P03182017.pdf.

<sup>&</sup>lt;sup>76</sup> Vigo et al. (2016). Estimating the true global burden of mental illness. Lancet Psychiatry, 3, 2, 171.

<sup>&</sup>lt;sup>77</sup> Flisher AJ et al. (1993). Risk-taking behaviour of Cape Peninsula high-school students. S Afr Med J, 83, 495.

Seedat S, et al. (2004). Trauma exposure and post-traumatic stress symptoms in urban African schools. Survey in Capetown and Nairobi. Br J Psychiatry, 184, 169.

<sup>&</sup>lt;sup>79</sup> Cooper PJ et al. (1999). Post-partum depression and the mother-infant relationship in a South African peri-urban settlement. Br J Psychiatry, 175, 554.

<sup>&</sup>lt;sup>80</sup> Carey PD. (2003). Trauma and posttraumatic stress disorder in an urban Xhosa primary care population: Prevalence, comorbidity, and service use patterns. J Nerv Ment Dis, 191, 230.

face considerable mental health challenges. However, the small size of these studies and the fact that many were conducted several years ago suggest that further research is needed to determine prevalence of mental health conditions in present-day South Africa.

While the prevalence of mental health challenges in South Africa is difficult to estimate accurately, the WHO notes that psychosocial and intellectual disabilities are becoming more widespread. By 2020, four out of the top ten causes of disability worldwide will be psychosocial or intellectual disabilities. Depression is expected to be the second leading cause of disability worldwide, behind only ischemic heart disease.<sup>81</sup> According to experts, that rise in South Africa may be even steeper due to comorbidities with HIV/AIDS, which is endemic in the country and due to high levels of violence which might contribute to PTSD. Other factors which also suggest that there will be a growing prevalence in South Africa include high levels of substance abuse and indications that the country is undergoing an epidemiological 'double burden', namely high levels of communicable diseases combined with increases in non-communicable conditions.<sup>82</sup>

Section 39 of the MHCA regulations requires that a national mental health patient register is kept, documenting the users in all establishments that render mental health care services. However, this has thus far not been operationalised, meaning that there remains a lack of reliable data. Even if the register was operational, it would provide only limited data because it records information that is applicable to hospitalised MHCUs only. There is no obligation to register or document community-based MHCUs. Therefore, the data recording system in relation to mental health requires significant improvement.

As a result of the need for information to follow-up from the SASH study and to supplement the national register, a key priority of the NMHPF is the improvement of mental health surveillance systems, research and innovation. Among the changes that have been envisaged or already implemented are the inclusion of mental health indicators in the District Health Information System (DHIS). This data is collected locally, and while it has been seen as a necessary and important improvement to health systems data collection in South Africa, challenges in its rollout in some health establishments continues to be a problem. Moreover, qualitative information cannot be captured through such a system, suggesting that additional research data is required on the actual quality of care provided.

# The treatment gap in South Africa

Despite the high prevalence of mental conditions described above, many South Africans who would benefit from accessing services do not receive treatment. According to SASH only 25% of South Africans living with a mental condition access services.<sup>83</sup> A number of factors have been associated with the treatment gap in South Africa including:

- a. insufficient budget allocation;
- b. poor mental health literacy and lack of information;
- c. stigma and discrimination;
- d. lack of available human resources;
- e. insufficient facilities providing mental health services;
- f. unavailability of child and adolescent services;
- g. inconsistent availability of medication; and
- h. limited mental health service availability in the criminal justice and correctional system.

<sup>81</sup> WHO. (2001). Mental disorders affect one in four people. http://www.who.int/whr/2001/media\_centre/press\_release/en/

<sup>&</sup>lt;sup>82</sup> Jack et al., as above.

<sup>83</sup> Seedat, S., Stein, D. J., Herman, A., Kessler, R., Sonnega, J., Heeringa, S., Williams, D. (2008). Twelve-month treatment of psychiatric disorders in the South African Stress and Health Study (World Mental Health Survey Initiative). Soc Psychiatry Psychiatr Epidemiol, 43(11), 889-897. doi:10.1007/s00127-008-0399-9.

### **Budget allocation for mental health**

Figures for budgeting for mental health are complicated by the fact that these decisions are made at the provincial level, meaning budgeting for mental health differs from province to province and there is, in effect, no minimum level of allocation. Regardless, budgeting for mental health in South Africa, like the rest of the world, is extremely low given prevalence numbers. A 2014 report stated that just 4% of the national health budget was disbursed for mental health services in South Africa.<sup>84</sup> This compares with 10.8% in the United Kingdom (UK) and 0.06% in India, demonstrating that, while under-resourcing is a significant barrier, it is not a uniquely South African problem.<sup>85</sup> Chapter 6 of this report, detailing submissions from the National and Provincial Departments of Health and National Treasury to the Commission's hearing, examines the issue of budgeting for mental health in greater detail.

### Mental health literacy and lack of information

A key focus of the CRPD is awareness-raising relating to the rights of people with disabilities.<sup>86</sup> This is particularly important for people with psychosocial and intellectual disabilities, many of whom require support in order to advocate for their rights and ensure that they are protected. Thus it is essential for a state seeking to meet its obligations under the Convention to ensure that it engages with the public on the subject of psychosocial and intellectual disabilities and specifically on the rights of this population.

Access to information is an important way in which people with psychosocial and intellectual disabilities can make decisions regarding their treatment and can engage with others as self-advocates. Provision of information that is comprehensible and that meets specific language and cultural requirements is therefore, a significant obligation of states under the CRPD.<sup>87</sup>

Research has shown that mental health literacy is poor in South African communities, with very little information being readily available to improve this.<sup>88</sup> Awareness-raising is carried out by various civil society bodies, including the South African Federation for Mental Health (SAFMH) and the South African Depression and Anxiety Group (SADAG), at times supported by government funding, but a systematic and coordinated nationwide mental health literacy drive or campaign relating to the rights of people with disabilities has not yet been implemented by the state party in terms of the CRPD.<sup>89</sup>

Mental health literacy has been shown to be a key determinant of actual help-seeking when a person is in distress. <sup>90</sup> Lack of knowledge about mental health challenges can be a significant barrier to improving conditions for people with intellectual and psychosocial disabilities because it may have the effect of leaving them unaware of options for treatment, thus prolonging impairment unnecessarily. <sup>91</sup> Mental health literacy is also hampered by the fact that most information on mental health is provided in English and not the other official South African languages.

Tromp B et al. (2014). SA's sick state of mind. http://www.sadag.org/images/pdf/sa\_s\_sick\_state\_of\_mind.pdf

 $<sup>^{85} \</sup>quad \text{DASRA. (2016). Mind the GAP. } \textbf{https://www.dasra.org/sites/default/files/Mental-Health-Report\_0.pdf}$ 

<sup>&</sup>lt;sup>86</sup> Article 8 of the CRPD.

<sup>&</sup>lt;sup>87</sup> United Nations General Assembly. (2016). Enhancing the accessibility of information and technology and inclusive development. UN Doc CRPD/CSP/2016/4.

Petersen I & Lund C. (2011). Mental health service delivery in South Africa from 2000 to 2010. South African Medical Journal, 101, 751.

<sup>&</sup>lt;sup>89</sup> South African Human Rights Commission. (2018). National Human Rights Institution Report on the South African Government's Initial Country Report under the International Convention on the Rights of Persons with Disabilities

<sup>&</sup>lt;sup>90</sup> Atilola O. (2016). Mental health service utilization in sub-Saharan Africa: Is mental health literacy the problem? Global Health Promotion, 23, 2, 30.

<sup>91</sup> Ibid.

# Stigma and discrimination

Stigma and discrimination are significant obstacles for people with intellectual and psychosocial disabilities at various levels. Demonstrating the way in which stigma and discrimination can result in under-prioritisation at the political level, the US Surgeon General states:

# The most significant obstacle to mental health parity is stigma... Stigmatisation of mental illness is an excuse for inaction<sup>92</sup>

Stigma also plays out at the level of communities and health care facilities, acting as a factor that discourages the participation of people with intellectual and psychosocial disabilities in society and that deprives them of access to quality health care.<sup>93</sup> Stigma within families has also been documented, and this can have the effect of those affected being denied access to the same opportunities or to the same cultural, community or family life as others are able to access.<sup>94</sup>

Considerable obstacles with regard to education and work opportunities for people with intellectual and psychosocial disabilities have also been documented, demonstrating the fact that stigma and discrimination can have deleterious effects on all aspects of life. In South Africa, an estimated half a million children with intellectual and psychosocial disabilities are out of school, a violation of a constitutionally enshrined right, not subject to progressive realisation. Exclusionary education systems have perpetuated stigma by placing students in 'special' schools, and even when mainstreamed into inclusive education facilities, children with intellectual and psychosocial disabilities often are not provided with the supports they need to succeed. Second

This system of exclusion is perpetuated when people with intellectual and psychosocial disabilities are denied the right to work, because of a lack of reasonable accommodations or because they were unable to transition out of an inadequate educational system. Negative attitudes among employers and co-workers can be factors that discourage people with disabilities from remaining in employment.<sup>97</sup> Higher rates of unemployment and poverty among people with disabilities suggest that this is a major challenge.<sup>98</sup>

Thornicroft et al. refer to stigma as a problem with three dimensions. Firstly, stigma is a problem of knowledge, whereby a sheer lack of information or a lack of substantive engagement with people with psychosocial disabilities leads to ignorance. Secondly, stigma is a problem of attitudes, characterised by inherently prejudicial beliefs about the disabled or false attributions regarding their disability (e.g. the belief that mental health conditions are a result of witchcraft). Thirdly, stigma is a problem of behaviours, that is, the act of discrimination itself that manifests in social exclusion, avoidance or laws and policies that treat people with intellectual and psychosocial disabilities as unequal members of society.<sup>99</sup>

Another important consideration insofar as stigma is concerned is the problem of self-stigma, or a person's individualised negative beliefs about him or herself. Self-stigma has received increasing attention in recent years because of the impact it can have on the lived experiences of people with intellectual and psychosocial disabilities. It can have an influence on the self-esteem of the individual and can result in numerous adverse consequences such as avoidance of social situations, a belief that one's condition cannot be overcome

<sup>&</sup>lt;sup>92</sup> United States Department of Health and Human Services Substance Abuse & Mental Health Services Administration. (1999). Mental Health: A Report of the Surgeon General, 3.

<sup>93</sup> Chikaodiri AN (2009). Attitude of Health Workers to the Care of Psychiatric Patients. Annals of General Psychiatry, 8, 19.

<sup>&</sup>lt;sup>94</sup> Arboleda-Florez F. (2003). Considerations on the Stigma of Mental Illness. Canadian Journal of Psychiatry, 48, 645.

<sup>95</sup> Department of Women, Children and People with Disabilities. (2013). Baseline Country Report to the United Nations on the Implementation of the Convention on the Rights of Persons with Disabilities in South Africa.

<sup>&</sup>lt;sup>96</sup> Winzer MA. (1993). The History of Special Education: From Isolation to Integration. 44-75.

<sup>97</sup> Manning C & White PD. (1995). Attitudes of Employers to the Mentally III. Psychiatric Bull, 19, 541.

<sup>&</sup>lt;sup>98</sup> Department of Social Development, as above.

<sup>&</sup>lt;sup>99</sup> Thornicroft G et al. (2007). Ignorance, Prejudice or Discrimination? Br J Psychiatry 190, 192-3.

resulting in lack of seeking health care services, or non-attendance of school.<sup>100</sup> Self-stigma is therefore, a considerable barrier to reaching the highest attainable standard of physical and mental health.

It goes without saying that addressing stigma primarily requires optimal person-centered mental health care, however, it also requires an approach that takes into account knowledge, attitudes and behaviours among others as well as the internalization of stigmatizing attitudes, rather than approaches that only address one or two of these co-occurring phenomena. This is important as South Africa, through the NMHPF, embarks on the process of rolling out anti-stigma initiatives. However, research suggests that there has not been sufficient resourcing or capacitation at provincial levels to actually carry out any programming, with the result that the stigma-related goals of the NMHPF remain largely unrealised.<sup>101</sup>

### **Human Resources for Health (HRH)**

The public mental health care system in general lacks adequate coverage of mental health professionals. Per 100,000 people, South Africa has 0.28 psychiatrists, 0.32 psychologists, 0.4 social workers, 0.13 occupational therapists and ten mental health nurses. 102 As a comparison, the average for a middle-income country would be five psychiatrists per 100,000 people. These numbers also do not disaggregate between rural and urban service provision. However, specialised mental health services have been shown to be concentrated in urban areas. 103

The levels of staffing in public mental health facilities are, overall, inadequate, but research demonstrates that rural areas and less affluent provinces are particularly poorly equipped to provide services. In KwaZulu-Natal, for example, of the 32 psychiatrists who were reported to be working in the public sector in 2011, just six were working outside of urban centres.<sup>104</sup> In 2017, the South African Society of Psychiatrists (SASOP) reported that there were just six psychiatrists working in the entire public mental health system in Limpopo province, and that facilities such as Hayani specialist mental health hospital did not have a psychiatrist on staff.<sup>105</sup> Even within urban centres, shortages are a challenge, however, as demonstrated by the fact that Ekurhuleni municipality in Gauteng has just one psychiatrist on staff.<sup>106</sup>

There have been efforts aimed at making mental health care more accessible in rural areas and retaining qualified staff. Among these efforts are the designation of 'priority' areas for community service rotations; the qualification of some community-based work to count towards Continuing Professional Development requirements, as stipulated by the Health Professions Council of South Africa (HPCSA); the introduction of the 'Registered Counsellor' category of professional, also known as the BPsych degree, which requires fewer years of clinical or experiential training than that required by a psychologist; and the introduction of the Occupation Specific Dispensation (OSD) for highly-skilled workers. However, in 2017, SASOP reported that just 35 psychiatrists qualify annually throughout the country and the majority go on to engage in private sector work.<sup>107</sup>

Authors such as Lund et al. have demonstrated that the vast majority of mental health service provision in the public sector is provided by nursing staff.<sup>108</sup> New policy directives have also expanded the role of lay

<sup>100</sup> Watson AC et al. (2007). Self-stigma in People with Mental Illness, Schizophrenia Bulletin 33, 6, 1312.

Marais DL & Petersen I. (2015). Health System Governance to Support Integrated Mental Health Care in South Africa: Challenges and Opportunities. Int J Mental Health Syst, 9, 1.

Lund C et al. (2010). Public sector mental health systems in South Africa: inter-provincial comparisons and policy implications. Social Psychiatry and Psychiatric Epidemiology, 45, 3, 393.

<sup>&</sup>lt;sup>103</sup> Burns JK. (2011). The Mental Health Gap in South Africa-A Human Rights Issue. Equal Rights Review, 6, 99.

<sup>&</sup>lt;sup>104</sup> Ibid.

<sup>&</sup>lt;sup>105</sup> The Times. (2017). Conditions at psychiatric hospitals 'appalling': doctors. https://www.timeslive.co.za/news/south-africa/2017-06-28-conditions-at-psychiatric-hospitals-appalling-doctors/

Nhlapo Z. (2017). Being Poor and Mentally III In South Africa Equals Being Pretty Much Screwed. http://www.huffingtonpost.co.za/2017/07/31/being-poor-and-mentally-ill-in-south-africa-equals-being-pretty\_a\_23057607/

<sup>107</sup> SASOP. (2017). Recovery plan for the Gauteng Department of Health. https://www.sasop.co.za/Content/Docs/Media\_ Statement\_Recovery\_plan\_for\_GDOH.pdf

<sup>108</sup> Lund et al., as above.

counsellors, community mental health workers and other forms of support staff (an internationally recognised model, known as 'task-sharing'). Research has illustrated that models such as these have the potential to improve adherence to medication in the case of chronic conditions such as HIV/AIDS, but also noted that there is a lack of standardised training for lay counsellors and poor supervision and logistical support have been barriers to utilising these models to their full effect.<sup>109</sup>

While there is clearly a shortage of skilled professionals overall, the disparities in the South African health care system's dual public and private models also apply to mental health. 86% of the country's psychologists are in private practice, while it has been reported that there are actually more than twice as many psychiatrists in the private health care system than in the public sector. Thus, a significant factor in addressing accessibility of mental health care and equality in the mental health system requires consideration of the role that socioeconomic status can play in access to services. Hence the title of a recent media report 'Being poor and mentally ill in South Africa equals being pretty much screwed'. Projects such as PRIME are focusing specifically on providing scalable solutions to the mental health 'treatment gap' in low and middle-income countries, with some demonstrated success, particularly using 'task-sharing' models that employ the services of CHWs and generalist health care workers, supervised by specialist mental health practitioners. Their findings may, therefore, potentially improve outcomes in the long-term.

Religious and traditional healers are also an important part of the workforce that provides mental health care services in South Africa, often as frontline service providers. Research has demonstrated that as many as 48.1% of MHCUs in Africa utilise religious or traditional practitioners as their first point of contact for seeking assistance,<sup>114</sup> demonstrating the significance of these providers in South Africa's mental health care landscape. Efforts to reach the Traditional Health Practitioners' Council were not fruitful, and statistics regarding the number of traditional healers in South Africa remain difficult to obtain. Nonetheless, the NDOH has acknowledged that engagement with traditional healers is necessary, particularly in the context of a shortage of HRH and particularly, also, in the context of a shift towards community-based PHC service provision.

## **Facilities providing mental health services**

In total, there are 22 specialist public mental health facilities in South Africa.<sup>115</sup> Public mental health infrastructure also varies from province to province. For example, the NMHPF states that the Northern Cape has six outpatient clinics and one psychiatric hospital, whereas the Eastern Cape hosts 700 outpatient clinics and five psychiatric hospitals.<sup>116</sup> South Africa is in the process of integrating public mental health services into PHC to facilitate care in the community. The Esidimeni tragedy illustrates that community-based residential or step-down facilities are also significantly under-resourced and that regulation of these facilities is poor, a situation that has been reported in previous studies.<sup>117</sup>

A 2017 report by the SASOP stated that there are currently no provinces that have effectively implemented community-based service provision, <sup>118</sup> while a 2012 study noted that, beyond medication monitoring, there

Petersen I et al. (2014). Optimizing lay counsellor services for chronic care in South Africa. Patient Education and Counselling, 95, 2, 201.

Tromp B et al. (2014). SA's sick state of mind. http://www.sadag.org/images/pdf/sa\_s\_sick\_state\_of\_mind.pdf

<sup>111</sup> Lund et al., as above.

<sup>&</sup>lt;sup>112</sup> Nhlapo, as above.

<sup>&</sup>lt;sup>113</sup> Brooke-Sumner C et al. (2017). Community-based psychosocial rehabilitation for schizophrenia service users in the North West Province of South Africa: A formative study. Social Work in Mental Health, 15, 3, 249.

<sup>&</sup>lt;sup>114</sup> Burns JK & Tomita A. (2015). Traditional and religious healers in the pathway to care for people with mental disorders in Africa: a systematic review and meta-analysis. Social psychiatry and Psychiatric epidemiology, 50, 6, 867.

<sup>115</sup> Tromp et al, as above.

<sup>&</sup>lt;sup>116</sup> NMHPF, as above.

<sup>117</sup> Lund et al, as above.

<sup>118</sup> The Times, as above.

was little community-based psychosocial rehabilitation taking place in South Africa.<sup>119</sup> Lund et al. found that infrastructure for conducting the 72 hour assessment required by the MHCA (to determine the need for institutional care) was 'mostly inadequate'.<sup>120</sup> Other shortcomings relate to facilities for children and adolescents, with Limpopo and Eastern Cape provinces having no such facilities, resulting in children and adolescents being housed in adult wards.<sup>121</sup> Child and adolescent psychiatry services are especially underresourced, representing just 1% of the total expenditure on mental health, with the result that minors are often treated in adult wards or even in juvenile detention centres.<sup>122</sup>

Public hospital beds for mental health have been steadily decreasing in number, with a 7.7% reduction between 2000 and 2005. In 2012, it was reported that, notwithstanding the potential cost reductions at tertiary levels accruing because of reducing bed numbers, savings were not channelled to community-based care or even district hospital levels, where there were just 0.3 mental health beds for every 10,000 people. In this highlights what psychiatrist Jonathan Kenneth Burns refers to as the impression that the government does not value psychiatric services and is prepared to sacrifice the expansion of psychiatric services in order to maintain general hospital services'. Similarly, the SASOP report highlighted a lack of actual beds, and non-use of others due to flooding in one hospital, as well as lack of food and water in a number of facilities. In some instances, beds are occupied by users who should have been discharged, limiting availability.

The quality of many facilities was also called into question. For example, several MHCUs who died during the GMHMP suffered hypothermia because of the lack of heating in NGO facilities, while others died from malnutrition.<sup>127</sup> A 2015 report by the Rural Mental Health Campaign (RMHC), a conglomeration of several NGOs, noted that mental health services were largely inaccessible in South Africa's rural areas, where roughly half of the country's population is located. It called for a distinction to be drawn in national policy and practice between 'rural' and 'urban' service delivery, paying specific attention to the fact that health care workers were needed and to the fact that there continues to be a need for stigma reduction targeting rural communities.<sup>128</sup>

# Child and adolescent mental health services

Epidemiological studies in high, middle and low income countries indicate that approximately one in five children and adolescents have some form of intellectual or psychosocial disability. In South Africa, definitive data is difficult to obtain but one report by the DSD noted that 27.5% of children between the ages of zero and four had some form of disability. A 2006 study estimated an overall adjusted prevalence rate of 17% for mental health challenges in childhood or adolescence. One of the countries indicate that approximately one in five children and adolescents and adolescents are children and adolescents and adolescents are children and adolescents and adolescents are children and adolescents and adolescents.

In South Africa, HIV infection, substance use, and exposure to violence increase vulnerability to mental health challenges. Against this backdrop, a 2012 study noted 'stark realities of unmet need' with regard to child and adolescent mental health care in South Africa, and called for an urgent scaling up of services to fulfil the constitutional rights of children and adolescents to appropriate mental health care.<sup>131</sup>

<sup>119</sup> Lund et al, as above.

<sup>&</sup>lt;sup>120</sup> Ibid.

<sup>&</sup>lt;sup>121</sup> The Times, as above.

<sup>122</sup> Tromp et al, as above.

<sup>&</sup>lt;sup>123</sup> Burns, as above.

<sup>124</sup> Lund et al., as above.

<sup>&</sup>lt;sup>125</sup> Burns, as above.

<sup>&</sup>lt;sup>126</sup> The Times, as above.

OHO, as above.

<sup>128</sup> Rural Mental Health Campaign. (2015). The Rural Mental Health Campaign Report: A call to action.

Department of Social Development. (2013). Baseline Country Report to the CRPD. http://www.dsd.gov.za/index.php?option=com\_docman&task=doc\_download&gid=673&Itemid=39

<sup>&</sup>lt;sup>130</sup> Kleintjies S et al. (2006). The prevalence of mental disorders among children, adolescents and adults in the Western Cape, South Africa. South African Psychiatry Review 9, 157.

<sup>&</sup>lt;sup>131</sup> Flisher AJ et al. (2012). Child and adolescent mental health in South Africa. Journal of Child and Adolescent Mental Health, 24, 2, 149.

The Department of Basic Education (DBE), in consultation with the NDOH and DSD has developed a Screening, Identification, Assessment and Support (SIAS) tool to identify learners who may need special supports because of intellectual or psychosocial disabilities. The departments are also collaborating on the Integrated School Health Programme (ISHP), an initiative aimed at conducting regular assessments and providing comprehensive health care to children in school-based settings, including psychosocial supports, intended to be rolled out to all schools by 2019.<sup>132</sup>

Some barriers have been noted with regard to the implementation of the ISHP, including fear of stigma and discrimination, <sup>133</sup> organisational challenges and the lack of skilled personnel. <sup>134</sup> Similarly, in health care settings, a significant shortage of HRH has been noted as a significant barrier to access to mental health care for children and adolescents with intellectual and psychosocial disabilities. <sup>135</sup> Further, there are limited opportunities for children and adolescents with intellectual disabilities to access education or skills development, this omission "reduces chances of obtaining paid employment for people with intellectual disability". <sup>136</sup> There is therefore a need "to develop community based education, training and leisure options that will further the competence of persons with intellectual disabilities to become more self-reliant at home and provide opportunities for them to engage in activities outside of the home... Failure to do so will result in many persons needing higher levels of care and at greater cost than might otherwise be the case."<sup>137</sup>

Reports have also surfaced of children and adolescents being housed in mental health facilities which had been intended for adults, leaving them at risk of abuse. This was reportedly because of a lack of available mental health beds for children and adolescents.<sup>138</sup> Such actions contravene provisions against cruel, inhumane and degrading treatment as well as protection from harm in, among others, the Constitution and the Convention on the Rights of the Child (CRC), requiring immediate rectification.

#### **Availability of medication**

Guided by the standards of the WHO, the NDOH operates an Essential Medicines List, which mandates health facilities to provide listed medications to health care users. The list is updated on a semi-annual basis. Several psychotropic medications are included on this list, including treatments for depression, anxiety and psychotic disorders. While this has the intention of ensuring access to medication for all who require it, there have been several instances of stock outs of essential medicines noted throughout South Africa. In 2015, the RMHC noted that medication stock outs were a significant challenge in rural parts of the country, leaving people with psychosocial and intellectual disabilities in these areas vulnerable to relapse and possibly also to abuse. It was also submitted that a very limited number of different types of psychotropic medicine is available from NDOH facilities, specifically far less options than are available to mental health care users accessing the private sector.

Department of Health. (2014). Integrated School Health Programme.

<sup>133</sup> Strauss M. et al. (2015). A qualitative analysis of the barriers and facilitators of HIV counselling and testing perceived by adolescents in South Africa. BMC Health Services Research, 15, 250.

Janse van Rensburg A & Rau A. (2017). Assessment of the Integrated School Health Programme in rural South Africa: A qualitative study using Normalisation Process Theory. Centre for Health Systems Research & Development, University of the Free State.

<sup>&</sup>lt;sup>135</sup> Flisher et al., as above.

Judith McKenzie and Roy McConkey. (2015). Caring for Adults with Intellectual Disability: The Perspectives of Family Carers in South Africa, University of Cape Town.

<sup>&</sup>lt;sup>137</sup> Ibid.

<sup>&</sup>lt;sup>138</sup> IOL. (2017). Shocking review on state of mental health services in SA. https://www.iol.co.za/lifestyle/health/mind/shocking-review-on-state-of-mental-health-services-in-sa-10006214

Medecins sans Frontieres. (2016). Essential drugs. http://refbooks.msf.org/msf\_docs/en/essential\_drugs/ed\_en.pdf

Stop Stockouts Project. (2014). 2014 Stockouts Survey. http://www.msf.org/sites/msf.org/files/stockouts\_2014\_final\_online.pdf

<sup>141</sup> RMHC, as above.

#### Mental health in the criminal justice and correctional system

Mental health services for survivors of crime and violence are reportedly very limited and have been characterised as 'cursory'. For rape survivors, mental health services are largely provided by NGOs, which are under-resourced and under-capacitated. Similarly, witnesses in the criminal justice system are often not afforded the support they need to overcome the traumatic experiences recounted. Abortages of skilled professionals affect the ability of the DOJCD and the SAPS to ensure that mental health services are provided in a manner that is adequate, resulting in complicated traumas which are often left unaddressed. Similarly, the ability of the SAPS to conduct investigations has been hampered by the lack of skilled staff.

A 2012 study found that 55.4% of all incarcerated people interviewed in one prison exhibited signs of a diagnosable mental health condition. For prisoners with life sentences, the estimated rate of prevalence was 78.4%. Alarmingly, 40% of all deaths in correctional facilities are attributable to suicide, suggesting a mental health component. The statistics speak to the urgent need to consider how mental health challenges manifest in correctional settings. Prisons in South Africa are extremely overcrowded, with high rates of violence and sexual assault, contributing to the epidemic of mental health challenges. Access to mental health care services is extremely limited, with HRH being in very short supply and prison officials lacking the necessary training to identify mental health conditions or to assess the need for intervention. Worse still, research suggests that there remains a large proportion of mental health challenges which go 'undetected' in South Africa's prisons, suggesting that the crisis might be worse than reported.

In 2016, reports emerged of so-called 'state patients' (i.e. people declared unfit to stand trial or found not criminally responsible because of their illness or 'mental defect') being transferred to correctional facilities because of a lack of beds in mental health hospitals. The Port Elizabeth High Court required the Department of Correctional Services in the Eastern Cape to conduct an audit of all such patients wrongfully incarcerated and develop plans to ensure that alternatives would be provided. In October 2017, the Department reported that 89 people with intellectual and/or psychosocial disabilities were being held in prisons, and that just one of them had access to a psychiatrist. The Department of Health in that province has established plans to develop forensic mental health infrastructure. Even so, reports indicate that this phenomenon is widespread across the country, highlighting the need for urgent attention to be paid to the development of forensic mental health infrastructure.

<sup>142</sup> Vetten L. (2015). It Sucks'/'It's a Wonderful Service' Post-rape care and the micro-politics of institutions. Johannesburg: Shukumisa Campaign and Action Aid South Africa.

Abrahams N & Gevers A. (2017). A rapid appraisal of the status of mental health support in post-rape care services in the Western Cape. South African Journal of Psychiatry, 23, 1, 2017.

<sup>&</sup>lt;sup>144</sup> Sukeri K et al. (2016). Forensic mental health services: Current service provision and planning for a prison mental health service in the Eastern Cape. South African Journal of Psychiatry, 22, 1, 787.

ENCA. (2017). Skills vacuum: Only one clinical psychologist left in SAPS. https://www.enca.com/south-africa/skills-vacuum-only-one-clinical-psychologist-left-in-saps

Naidoo S & Mkize DL. (2012). Prevalence of mental disorders in a prison population in Durban, South Africa. African Journal of Psychiatry, 15, 1, 30.

Prinsloo J. (2013). Offenders with mental disorders in a South African prison population: profiling the behavioural characteristics on mental illness. J Psychology in Africa, 23, 133.

Ncana N. (2010). Violence in prisons out of control, admits government. The Times, 23 May 2010.

<sup>&</sup>lt;sup>149</sup> Bantjes et al. (2017). Human rights and mental health in post-apartheid South Africa: lessons from health care professionals working with suicidal inmates in the prison system. BMC International Health and Human Rights, 17, 29.

<sup>&</sup>lt;sup>150</sup> Naidoo & Mkize, as above.

<sup>&</sup>lt;sup>151</sup> Ellis E. (2017). Court calls for list of mental patients in jails. http://www.heraldlive.co.za/news/2017/10/02/court-calls-list-mental-patients-jails/

<sup>&</sup>lt;sup>152</sup> Ellis E. (2017). Mental patients locked in cells together, court told. http://www.heraldlive.co.za/news/2017/10/14/mental-patients-locked-cells-together-court-told/

<sup>153</sup> Medical Brief. (2017), Wrongful incarceration case exposes Eastern Cape mental health crisis. https://www.medicalbrief.co.za/archives/wrongful-incarceration-case-exposes-eastern-cape-mental-health-crisis/

# 4.

# PROCEDURES OF THE SAHRC HEARING

# Composition of the panel

he panel consisted of the following members:

- I. Adv. Bongani Majola, Chairperson of the South African Human Rights Commission
- II. Ms Angie Makwetla, Commissioner of the South African Human Rights Commission
- III. Adv. Bokankatla Joseph Malatji, Commissioner of the South African Human Rights Commission
- IV. Professor Katherine Sorsdahl, Co-director of the Alan J. Flisher Centre for Public Mental Health at the University of Cape Town.

# Participation of people with psychosocial disabilities and/or their representatives

Recognising the importance of the participation of people with intellectual and psychosocial disabilities in these proceedings, as with all matters which are relevant to them, the Commission, through its stakeholder engagements prior to the hearing, sought to ensure that adequate consultation took place with DPOs and other relevant actors. Engagements also took place with the Life Esidimeni Family Committee and with members of the Section 11 advisory committee on the rights of persons with disabilities, whose input was invaluable in formulating the questions posed during the hearing and in shaping the goals and aspirations of the SAHRC with regard to the outcomes of this process.

# Nature and structure of the proceedings

The proceedings were inquisitorial in nature. Respondents were obligated to make written and oral submissions. Before the respondents could make their submissions to the Commission, they were formally placed on record, by either taking the prescribed oath or affirming that their submissions were true and binding on their conscience. The submissions made by the respondents were in response to the questions posed in their respective invitations. After hearing the oral submissions, the panellists had the opportunity to ask further questions of clarity pertaining to the submissions.

# 5.

# SUBMISSIONS FROM RESPONDENTS

# National Department of Health (NDOH)

he NDOH provided the Commission with a report outlining progress in the implementation of the recommendations of the OHO. The Department detailed a process of rapidly assessing 1,250 MHCUs housed in NGOs and CBOs which had been licensed by the Gauteng Department of Health. 20 out of the 27 facilities licensed were deemed to not be fit for purpose. This resulted in 764 MHCUs housed in these facilities, many of whom had been transferred from Life Esidimeni, being moved into alternative facilities. 14 NGOs were shut down completely during this process. According to the report, 99 MHCUs had not been transferred from facilities identified as inadequate, for reasons that included acute phase conditions, family refusal, patient refusal and a pending legal dispute with one of the NGOs.

The NDOH submitted that it allocated budgeting for health care in the provinces according to a pre-determined formula based on the demographics of each province. The NDOH did not have any specific role to play in deciding how those budgets were spent, including what proportion of each province's budget was allocated for mental health. In 2014, the NDOH sought the legal opinion of state law advisers to ascertain whether the national department may take a more active role in the provision of services, a competency of provinces and local governments in terms of Schedule 4 of the Constitution. The opinion concludes that:

...to embark on an extensive and time-consuming legislative exercise of amending the Constitution and adopting or amending national legislation to vest the national government with exclusive legislative competence with regard to health services merely because a few provinces and municipalities have reportedly failed to discharge their responsibilities effectively in this regard would not be in the best interest of protecting, promoting, improving and maintaining the health of the population in the national, provincial and local spheres of government.

The opinion essentially discourages the intervention of national government by way of legislation, although it does recognise that, where the inaction of provinces might be considered to be 'unreasonable' or 'prejudicial', the national government's legislative intervention may be considered permissible under section 146(3) of the Constitution. As an alternative, the opinion suggests that national government and provincial governments exercise oversight of the rollout of health services through the development of essential standards, the setting of minimum requirements and through effective monitoring.

Prior to the NMHPF, the NDOH had published 'policy guidelines' relating to child and adolescent mental health, the conducting of 72-hour assessments in accordance with the MHCA and the seclusion and restraint of MHCUs. Following the report of the Mental Health and Poverty Project (MHAPP) in 2008, which found that

submissions fron respondents

mental health services were inadequate and under-prioritised, the NDOH began a process of consultations with stakeholders that eventually culminated in the National Mental Health Summit in 2012, which in turn informed the content of the NMHPF.

The NDOH did not provide monitoring reports for the period prior to the introduction of the NMHPF, thus suggesting that monitoring has been a fairly recent addition to the work of the department. The department did provide the Commission with reports relating to monitoring of implementation of the NMHPF, including site visits that were undertaken in all nine provinces. Importantly, these site visits took place after the GMHMP, and were in fact precipitated by the events that followed the transfer of MHCUs out of the Life Esidimeni facility. Thus, it appears that the first actual monitoring exercise undertaken by the NDOH in relation to the provision and quality of mental health services was actually in mid-2017.

The report of the monitoring exercise indicates that, while significant progress has been made at the policy level, implementation that is concordant with a human rights approach to mental health remains lacking. At the time of reporting, just three out of the nine provinces had a dedicated mental health directorate, as mandated by the NMHPF, and others questioned the need for such a directorate, suggesting instead that mental health ought to be integrated fully into primary health care strategies and plans. Split reporting lines demonstrated the fact that there remain a number of issues for which clarity still needs to be provided, and it is important to note that this particular challenge was reported to have significant implications for the level of priority that mental health was given within provincial departments of health.

The monitoring report also indicated that only Gauteng and the Free State had approved, costed and budgeted strategic plans for mental health. None of the provinces could provide a detailed budget for mental health, particularly community-based mental health which, under the NMHPF, is intended to be a priority. Gauteng was the only province that provided the NDOH with a budget for mental health services included in PHC, amounting to R224 375 700 or about 19% of the total mental health budget. Human resources were disproportionately concentrated in psychiatric facilities and planning for human resources, despite the policies provided to the Commission by the NDOH, was reportedly poor. In general, provision of psychotropics was considered to be good, but there were reports of stock outs 'as with the general health system'.

MHRBs in six of the nine provinces were 'poor' by the department's own assessment, and, with the exception of the Western Cape, were considered to be poorly resourced. The department acknowledges, in its report that this could result in significant human rights concerns. The report further notes that infrastructural plans are generally 'inadequate', with a continued over-reliance on psychiatric institutions. Despite the issuance of IUSS guidelines for mental health facilities in 2014, the department noted that 'current infrastructure generally does not meet national design specifications for mental health units and child psychiatry'. The report also notes that, in the Northern Cape and North West provinces, there have been significant outlays of expenditure for mental health infrastructure, but no facilities have been commissioned for use. The last known audit of Forensic Psychiatric observation facilities was in 2010, with the department's audit finding that a number of these facilities were considered 'intolerable' and therefore, in need of repair. In addition to infrastructure challenges, the NDOH also noted that other challenges included long wait times for state psychiatrists due to patient load and a resultant reliance on contractors; challenges in transporting forensic psychiatry users; and a need for clarity regarding the capacity of users under 18 in legal proceedings.

The NDOH report states that there is a 'general non-compliance...in relation to the licensing of community-based mental health facilities/centres'. Similarly, mental health stakeholder forums were found to be 'generally lacking in all provinces'. Training of medical officers and professional nurses in APC was reported to be occurring in a 'haphazard fashion'. The report also notes that 'the culture for analysing and using information for planning does not seem to prevail in any of the provinces'. Despite the importance placed on the integration of mental health care into PHC services, the Department's report noted that only a small fraction of districts had established DMHTs, meaning the support needed in frontline health care facilities was not being provided.

One of the key recommendations of the NDOH's report states the following:

There is a strong need for the national mental health directorate to provide oversight, support and mentorship to all provinces. To this extent, the directorate needs to be capacitated and resourced to optimally exercise its expected role. The Department should consider prioritising filling the existing vacant posts responsible for mental health infrastructure and oversight on psychiatric hospitals and Mental Health Review Boards.

The NDOH does not currently have any regulations regarding mental health parity in budgeting in provinces. The Department also has not engaged in the process of developing a policy regarding deinstitutionalisation. In keeping with the recommendation of the OHO that the Minister of Health appoint a team to review licensing regulations for NGOs and CBOs to whom MHCUs would be transferred, the Draft Guidelines for the Licensing and Regulation of Day-care Facilities for People with Mental and/or Intellectual Disabilities were published for public comment in May 2017, although it is not clear whether these have since been finalised following the closure of the public commenting period.

Regarding human resources, the department stated that it has implemented several measures aimed at improving the output, retention and distribution of specialised health professionals, including mental health care professionals. These include the OSD, which has significantly increased remuneration for professionals, the rural allowance, which was designed to improve the distribution of health care professionals, and the use of community service placements to enhance access to services. However, reviews of these processes revealed that they were inconsistently applied and that there remained a number of challenges in implementation that required further policy clarity as well as further technical capacity. The introduction of the Registered Counsellor category of professional was also cited as a potential source of additional human capacity to carry out mental health functions, although an examination of actual staff numbers indicates that provinces have not employed these professionals (although some have planned to in the near future). As a result, many universities have stopped offering this programme. As mentioned, despite these efforts, there remains a significant shortage of health professionals, particularly in more remote and rural parts of South Africa, including mental health professionals. In respect of training of community health workers, the department noted that a uniform training curriculum had been developed and that this curriculum contained information relating to mental health. The NDOH did not provide a specific HRH strategy for mental health.

Regarding data related to provision of mental health services, the department noted that the District Health Information System collected data from each district regarding the following:

- a. MHCUs under 18;
- b. MHCUs 18 and over;
- c. MHCUs total;
- d. Admissions under 18;
- e. Admissions 18 and over;
- f. Mental health admissions total;
- g. Mental health involuntary admissions;
- h. PHC clients screened for mental disorders; and
- i. PHC clients treated for mental disorders.

The following information was provided by the department regarding the indicators at each of the 11 pilot NHI sites:

Table 1: Number of clients that were screened for methal disorders

NHI PILOT DISTRICT	PHC CLIENTS SCREENED FOR MENTAL DISORDERS (N)		
	2015/16	2016/17	
a) OR Tambo (Eastern Cape)	84875	167075	
b) Thabo Mofutsanyane (Free State)	139427	504722	
c) Tshwane Metro (Gauteng)	318491	1756509	
d) Umzinyathi (KwaZulu-Natal)	11700	156351	
e) Umgungundlovu (KwaZulu-Natal)	36498	315074	
f) Amajuba (KwaZulu-Natal)	77483	451435	
g) Vhembe (Limpopo)	104052	521322	
h) Gert Sibande (Mpumalanga)	1393	181964	
i) Prixley KaSeme (Northern Cape)	2001	43176	
j) Dr Kenneth Kaunda (North West)	36073	195927	
k) Eden (Western Cape)	0	0	

Table 2: Number of mental clients that received treatment at PHC facilities

NHI PILOT DISTRICT	MENTAL HEALTH CLIE	NTS TOTAL (N)	
	2015/16	2016/17	
a) OR Tambo (Eastern Cape)	29281	31995	
b) Thabo Mofutsanyane (Free State)	2703	14761	
c) Tshwane Metro (Gauteng)	23300	67825	
d) Umzinyathi (KwaZulu-Natal)	21739	17657	
e) Umgungundlovu (KwaZulu-Natal)	38276	43433	
f) Amajuba (KwaZulu-Natal)	14844	42296	
g) Vhembe (Limpopo)	61677	66904	
h) GertSibande (Mpumalanga)	13188	11540	
i) Prixley KaSeme (Northern Cape)	6028	7164	
j) Dr Kenneth Kaunda (North West)	20980	22304	
k) Eden (Western Cape)	20519	19423	

Table 3: Number of mental health clients of all ages who attended ambulatory services at PHC facilities in the 11 NHI pilot sites

NHI PILOT DISTRICT	BASELINE (PRIOR PC 101 INTERVENTION) 2013/14	FOLLOW UP 2014/15	FOLLOW UP 2015/16	FOLLOW UP 2016/17
a) OR Tambo (Eastern Cape)	43031	46386	29281	31995
b) Thabo Mofutsanyane (Free State)	32744	32302	2703	14761
c) Tshwane Metro (Gauteng)	81046	78416	23300	67825
d) Umzinyathi (KwaZulu-Natal)	28311	21982	21739	17637
e) Umgungundlovu (KwaZulu-Natal)	35635	38283	38276	43433
f) Amajuba (KwaZulu-Natal)	30390	24977	14844	42296
g) Vhembe (Limpopo)	78556	77198	61677	66904
h) Gert Sibande (Mpumalanga)	20947	18879	15640	17667
i) Prixley KaSeme (Northern Cape)	11999	11737	6107	7246
j) Dr Kenneth Kaunda (North West)	32575	30191	20980	22304
k) Eden (Western Cape)	21186	21669	20519	19423

The Department further noted that qualitative indicators were included in the Norms and Standards Regulations applicable to different categories of Health Establishments. Indicators included respect for privacy of users, respect for diversity in relation to language, culture and ability and the establishment of patient 'experience of care' surveys in each district. Provision of information regarding patients' rights is also mandated under this policy. A complaints mechanism is also mandated. The quality indicators do not, however, include measures such as retention of MHCUs in care, self-reported improvements or declines in functioning, availability of accommodations such as interpreters or measures of stigma or self-stigma. Regarding the patient register required by section 39 of the MHCA regulations, the department did provide the Commission with a sample of its register, although it is not clear, from the department's submission, to what extent health establishments are in compliance with this requirement, potentially calling into question the quality and utility of the data.

Regarding stigma and discrimination, despite the reduction of stigma and the raising of mental health awareness being part of the NMHPF's strategic emphasis, the department did not provide information relating to its role at the national level as far as stigma reduction was concerned. A Draft Plan to Popularise and Initiate the Implementation of the Mental Health Policy Framework and Strategic Plan 2013-2020 does exist. This plan, however, relates to raising awareness of this strategic priority within the health system. Evidence of awareness-raising and stigma reduction policies and programming at the national level, in communities and within the general public, was not provided. The department did, however, note that it subsidises awarenessraising and community integration efforts of the SAFMH. Programming has been rolled out in four provinces, namely: Mpumalanga, Free State, Northern Cape and Limpopo. The SAFMH's 'empowerment sessions', which include the formation of user representative structures, are due to be rolled out in KwaZulu-Natal in 2018. The SAHRC was provided with a detailed report that demonstrates a significant amount of community engagement, but that also illustrates the continued challenge of under-resourcing. The SAFMH reported that it had discontinued its relationship with the NDOH and secured international funding to continue its community engagement work beginning in the 2018/2019 financial year. It is, therefore, not clear whether the NDOH will be allocating resources to further awareness-raising or stigma reduction initiatives. Monitoring and evaluation frameworks to ensure programmes that are being implemented to address stigma meet their objectives were not included in the Department's submission.

The department highlighted the need for deepening inter-sectoral collaboration and for improving relations between departments whose work intersected with its own. Collaborative relationships, particularly with the DSD, the SAPS, the DBE and the DOJCD would need to be fostered as reforms were undertaken.

# **Eastern Cape Department of Health**

The department stated that lack of community-based mental health facilities was a significant impediment to access to care for people with psychosocial and intellectual disabilities. In the Eastern Cape Province, all 15 licensed facilities are located in urban centres, leaving the rural population underserved. Integration of mental health care into PHC services is lacking, and this also has a negative impact on the ability of providers to promote good mental health. Stigma and discrimination, both within communities and within health care facilities, is still a major problem. Awareness of rights among MHCUs, including of the existence of the MHRB, remains poor, resulting in people often not claiming their rights.

The department also noted that there were shortages of HRH in rural parts of the province that infrastructure was inadequate for the purpose, and that budgeting for mental health was not meeting the needs of users. A deficiency of 1,600 psychiatry beds exists in the Eastern Cape, and there are particular shortages in the rural areas of the province. The province employs 16 psychiatrists, 37 psychologists, seven occupational therapists, 24 social workers and 403 psychiatric nurses. Budget data was available for psychiatric hospitals but not for community-based mental health care. The department also reported that 3 MHRBs operated in different regions of the province (Western, central and Eastern).

According to the NDOH's report on the implementation of the NMHPF, the Eastern Cape does not have a mental health directorate, with the province reporting that it intended to do so in the 2018/19 financial year.<sup>154</sup> This is true, also, of DMHTs, which the province intends rolling out over a period of three years. There is a draft strategic plan but this has not been costed as yet. The Eastern region MHRB has also had 'no appeals in the last five years'. The report also noted that MHRBs reported 'poor compliance with submission of application documents to the High Court'.

In correspondence addressed to the Commission from Dr TD Mbengashe, Superintendent General of the Eastern Cape provincial Department of Health, dated 20 June 2018, it was indicated that a Mental Health Directorate has now been established.

Mental health infrastructure in the Eastern Cape has been historically under-prioritised, and no beds exist for child and adolescent mental health services. Plans for community-based mental health care and deinstitutionalisation have not been compiled. There is an inter-sectoral forum in the province, but this is only for substance abuse.

# Free State Department of Health

There is one public psychiatric facility in the Free State (Free State Psychiatric Complex), with a total of 877 beds, as well as five private psychiatric facilities. Two generalist state hospitals also provide mental health care services, with 77 beds in total. There are five additional facilities for 72 hour assessments in terms of the MHCA. The department noted that there is a mental health directorate, and that the directorate is being capacitated in a phased manner. There is currently one district with a DMHT (Thabo Mofutsanyana) and two MHRBs (one for the north of the province and one for the south). Forensic facilities were reportedly 'dilapidated' and in urgent need of refurbishment. There were also no dedicated child and adolescent beds available in the public sector. Six NGOs are registered with DSD and none with the department, with another 55 licensed by DSD.

The department noted that a number of challenges prevailed, including poor budgeting for mental health services and slow progress on implementing community-based mental health care services. It also highlighted a 'lack of commitment and practical involvement of number of government and non-government sectors and partners'. It also noted that a review of the MHCA was required to clarify the independence and authority of the MHRB. There is also a need to address information and data gaps, including through an integrated interface that engages all departments engaging with people with psychosocial and intellectual disabilities. The department also suggested that conditional grants allocated for health should take into account the need for prioritisation of the 'burden of disease', including mental health.

According to the NDOH's report on the implementation of the NMHPF, the province has an interim mental health directorate, pending final approval and an approved strategic plan for mental health. Budget data at the district level was not available. The province has a total of 10 psychiatrists and 17 psychologists. According to the report, 'if a child over 12 years old needs admission, he or she is admitted in the adult ward'. The province also lacks guidelines for the licensing of NGOs and CBOs in terms of the MHCA regulations. The report also noted that there was a functioning provincial inter-sectoral forum and functioning forums in 2 districts.

# **Gauteng Department of Health**

According to the NDOH's report on the implementation of the NMHPF, there is a dedicated mental health directorate in Gauteng, as well as an approved and costed strategic plan. There is a dedicated budget for psychiatric hospitals and for community-based mental health. The department employs 48 psychiatrists, 74 psychologists and 36 occupational therapists. There is one interim MHRB for the province, with a plan for 4 more in the districts.

There are currently no mental health infrastructure plans apart from a planned upgrade to Charlotte Maxeke Johannesburg Academic Hospital. The province has 75 beds for child and adolescent MHCUs. Plans for deinstitutionalisation and community-based mental health infrastructure have been drafted but not approved. The province has no DMHTs. A provincial stakeholder forum exists, but large centres, including Johannesburg and Tshwane, do not have stakeholder forums. Nurses are asked to interpret for MHCUs where necessary.

The provincial department noted that guidelines did exist for the licensing of NGOs and CBOs to care for people with psychosocial and intellectual disabilities. Licensing is done by the mental health directorate and

the licensing department, while audits are done quarterly by the district and ad hoc unannounced visits also take place. Ad hoc auditing is also undertaken by the mental health directorate.

Among the factors assessed in the auditing and licensing procedures are the physical building's safety, security and proximity to health care facilities; food availability and preparation; assistive devices and equipment; stimulation, therapeutic and rehabilitation programs; occupational health and safety standards; medication; and care of clients. The department provided the Commission with copies of its monitoring, licensing and auditing reports, demonstrating that auditing has been taking place routinely. However, the reports also highlighted that licensing relied on recommendations from assessors, without standardisation. Therefore, there were instances of facilities where food was found to be unavailable or where rodent infestation had taken place which were recommended for licensure.

In its submission, the department noted that there was severe pressure on existing mental health care services and that existing facilities and services were not adequate for provision of comprehensive mental health care. Some challenges were noted with regard to medication availability and budget constraints reportedly hampered improvements, including in the recruitment of HRH. A 10-day mental health course is provided to PHC staff, but the department noted that refresher training was needed and this needed to be budgeted for.

# KwaZulu-Natal Department of Health

The department listed a number of challenges to the optimal delivery of mental health care services in the province, including lack of established DMHTs and inadequate infrastructure. It also highlighted the lack of residential facilities for MHCUs who had been deinstitutionalised and lack of adequate capacity for psychological services. Similarly, the department noted that there was a skewed distribution of specialised personnel in urban centres and psychiatric facilities. The department listed its key priorities for the next five years as: Development of infrastructure; recruitment of DMHTs; revitalisation of dilapidated infrastructure; and recruitment of skilled personnel.

According to the NDOH's report on the implementation of the NMHPF, there is a mental health directorate in the province, but not an approved, costed strategic plan for mental health. The budget for psychiatric facilities is clear but less so for community-based care, with increases below inflation each year. The department employs 26 psychiatrists with a 50% vacancy rate, with 86 psychologists and 36 occupational therapists are available. Four MHRBs cover 11 districts in the province, with the report noting that 'the majority of applications were not submitted to the High Court due to mistakes and delayed submission, resulting in illegal detention of users in hospitals'. Only KwaZulu-Natal Children's Hospital is considered 'fit for purpose' for underage MHCUs.

The department does not have a plan to support infrastructure for community-based mental health or for deinstitutionalisation. Draft guidelines for licensure of NGOs and CBOs have been circulated. 5 of the 11 districts have inter-sectoral forums.

# **Limpopo Department of Health**

The department stated that it had a user rate of 300 per 100,000 in psychiatric hospitals and that 37 out of the 40 hospitals are equipped for 72 hour assessments in terms of the MHCA. There are 3 specialist psychiatric facilities in Limpopo, with a total of 1,190 beds, although none of these have forensic facilities. One specialist psychiatrist is employed in these facilities, while there are 5 psychologists and 10 occupational therapists. There are four residential facilities operated by DSD in the province, while none are operated by the department. There is one private facility.

The department noted challenges including a shortage of key staff and a lack of sufficient budget to provide comprehensive services. Infrastructure is poor in the province and deinstitutionalisation is a challenge due to family refusals or untraceable relatives, as well as the lack of community-based facilities. The province proposed improving facilities at Evukaxeni Psychiatric Hospital, improving budgeting to hire clinical staff. In addition, the department has already planned forensic units at 2 psychiatric facilities and has submitted a plan for the establishment of community residential facilities for costing and incorporation into the provincial infrastructure plan.

According to the NDOH's report on the implementation of the NMHPF, Limpopo does not have a strategic plan for mental health and does not have a provincial mental health directorate. Some districts have MHRBs but these are not fully functional. 16% of general health facilities cater to MHCUs and there are currently no beds for children and adolescents. There is no deinstitutionalisation policy and no DMHTs have been formed. Data collection and utilisation reportedly is not uniform. There are stakeholder forums in two of the five districts.

# Mpumalanga Department of Health

The department submitted that several challenges hindered the realisation of the right to mental health care in Mpumalanga, including lack of skilled personnel, lack of infrastructure and lack of adequate budget to provide services. It also noted that mental health concerns were an increasing challenge in Mpumalanga and that stigma and discrimination in communities and among health care workers was an impediment to access to care. Rural areas of the province also required special attention. The department did not provide strategic plans as evidence of its activities.

According to the NDOH's report on the implementation of the NMHPF, the province does not have a mental health directorate. There is a draft strategic plan but this has only been partially implemented. The province does not have a psychiatric facility and has a 73% vacancy rate for psychiatrists. There are 23 psychologists in the province and eight registered counsellors and 3 occupational therapists.

There is one MHRB for the entire province due to recruitment challenges. The MHRB reported that MHCUs were housed in general wards after 72 hour assessments because of a lack of referral facilities and noted that communication with the MEC of the province was 'not transparent'. It also reported that 'the majority of applications were not submitted to the High Court due to mistakes and delayed submission, resulting in illegal detention of users in hospitals'. The report recommended making the MHRB a cost centre to improve resource allocation.

10.7% of generalist hospitals have facilities for psychiatric care and no beds are allocated for children and adolescents. The report notes that there are no community-based facility plans for the province and that some NGOs were operating services for MHCUs without licensure. One district has a DMHT. An inter-sectoral forum exists at provincial level but only for substance use. There was no other information regarding user participation.

# Northern Cape Department of Health

The department's submission illustrated that the largest proportion of funding for mental health is allocated to the province's one psychiatric facility-West End Tuberculosis and Psychiatric Hospital in Kimberley. Inconsistent data regarding the mental health sub-programme's budget (i.e. for services other than hospital care) suggests that figures may be inaccurate, although the figures provided to the Commission demonstrate intermittent over-spending and under-spending of the mental health budget from year to year. Within this sub-programme, the department reported that district mental health services were not budgeted as a separate cost centre and, therefore, could not be accurately estimated.

The provincial department reported that mental health services were provided at 40 mobile clinics, 165 PHC clinics, 11 district hospitals, one regional hospital and one tertiary specialised hospital. Across the province's five districts, the department reported that there were 5,749 MHCUs, although it also reported that one district, the Pixley ka Seme Municipality, had no MHCUs. There were 315 beds for MHCUs across the province. At district level, there were no psychiatrists on staff, with eight psychologists, 23 occupational therapists, 16 social workers and three psychiatric nurses. There were no DMHTs or MHRBs in any of the municipalities. At West End, the province reported having three psychiatrists on staff as well as six psychologists, five occupational therapists, two social workers and 16 psychiatric nurses as well as a functional MHRB.

There are some out-patient facilities for child and adolescent psychiatry but no inpatient facilities. While occupational therapists are available, they are not necessarily involved in mental health service provision. The province also reported that there was no budget to support mental health rotations for medical officers in training and that there were no registered NGOs or CBOs for adults with severe or profound intellectual disabilities. Stock outs are reportedly a problem, and user participation in mental health, as reported by the provincial department is significantly lacking. The province also currently does not have a mental health directorate.

According to operational and strategic plans, the provincial department of health intends developing an advocacy and awareness-raising programme in the 2018/2019 financial year, while also forming a mental health directorate and establishing MHRBs in all districts. An inter-departmental forum consisting of NGOs and other government departments exists at the provincial level, although the department did not furnish details of its activities. Similarly, operational plans provided by the department indicated that several activities were incorporated and budgeted for, including training of PHC staff on mental health, monitoring of compliance with laws and policies, community mobilisation and facilitation of 72 hour assessments. However, no information regarding performance against these targets was provided.

According to the NDOH's report on the implementation of the NMHPF, the efficacy of the province's system for monitoring medication stock outs was 'doubtful'. Interpreters provide assistance in the event of a need.

# North West Department of Health

The department submitted that there was a shortage of HRH and poor retention of staff. Infrastructure was non-compliant, and a lack of community residential facilities was noted. Poor access to services was cited as a problem, and relapse rates were noted as being high. The department did not furnish the Commission with information regarding the number of MHCUs in the province, the number of beds for mental health or any other specifics.

According to the NDOH's report on the implementation of the NMHPF, the North West province has a vacancy rate for psychiatrists of 66% and 25% for psychologists. The province does not have a mental health directorate and has one MHRB serving several health establishments. There are no DMHTs, and 23.5% of hospitals cater to MHCUs. PHC staff could not be released for mental health training due to staff shortages. There was also no training in indigenous languages for the provision of language-appropriate mental health care services and no stakeholder forums had been established.

After being provided with a provisional version of this Report the Northern Cape Department of Health subsequently advised that there are 919 mental health care users in the Pixley Ka Seme District Municipality. No documentation was provided to evidence or support this contention.

# Western Cape Department of Health

The department noted that the Western Cape was found to have the highest prevalence of psychosocial and intellectual disabilities in South Africa. Access to services was inadequate throughout the province, due to budget constraints and a severe shortage of HRH. The department noted that another challenge was the over-reliance on a 'curative' model of care rather than action to promote mental health. Youth in conflict with the law were also found to be especially susceptible to psychosocial and intellectual disabilities, and this required specialised attention. The department noted that stigma and discrimination constituted a significant barrier to access to care and community-based services were especially underserved. The department did not provide specific information regarding its activities to mitigate some of these challenges.

According to the NDOH's report on the implementation of the NMHPF, the Western Cape lacks a mental health directorate. Senior management for health in the province did not agree with the recommendation made by the NDOH as the province would rather focus on an integrated care platform. There is also no approved and costed strategic plan for mental health in the province. The province has 47 psychiatrists and 55 psychiatry registrars, along with 80 psychologists, 158 social workers and 40 occupational therapists. The report noted in relation to medication that 'occasional shortages and localised supply issues do occur'. The province has one MHRB. Guidelines for the licensing of NGOs do exist in the Western Cape. There are no DMHTs and there is an intersectoral forum, but this is specific to substance abuse.

# Department of Social Development (DSD)

The DSD failed to appear or provide submissions to the original hearing hosted by the SAHRC. Following issuance of a subpoena, the Department provided a substantive response along with an apology from the then Minister of Social Development. The DSD noted that, through its provincial subsidiaries, it was supporting 218 day care centres for people with disabilities and 146 residential facilities, many of which also provided home-based care. The number of centres varied between 67 in Gauteng and 8 in the Northern Cape, and DSD does not disaggregate facilities to determine if they provide specific support to people with psychosocial disabilities. The DSD runs substance abuse treatment facilities in Gauteng, the Western Cape, KwaZulu-Natal, Mpumalanga and the Eastern Cape. Facilities are being constructed in other provinces, although it is not clear when such facilities will be operational. Registration and monitoring of facilities is conducted by provincial departments, and DSD noted that 'several' provinces had not provided monitoring reports to determine the suitability of residential facilities.

The Department noted that it advocated for an 'integrated service delivery system', wherein mental health services were provided by the DOH. A psychosocial support programme does exist under the ambit of the DSD however, and the SAFMH has been provided funding to support 'protective workshops' aimed at providing sheltered work and stimulation opportunities for people with psychosocial and intellectual disabilities in the amount of R1.3 million in the 2015/16 financial year, R500,000 in the 2016/17 financial year and R1 million in the 2017/18 year. A total of 293 protective workshops have been conducted, 141 in urban areas, 34 in peri-urban areas and 118 in rural areas and 70% of participants were classified as people with intellectual disabilities. Regarding the Policy for the Provision of Social Development services to People with Disabilities, the Department noted that it was currently costing this programme, suggesting that provisions have not yet been made for implementation.

The DSD reported that it had not been consulted on the deinstitutionalisation process undertaken by the NDOH. Inter-departmental collaboration is fostered through quarterly meetings, particularly between the DSD, the DOH and the DBE. Regarding monitoring and evaluation, the DSD noted that quarterly meetings are held with provincial disability fora and that annual progress reporting has been instituted. However, reports detailing any resolutions or outcomes from such fora were not provided.

Data regarding the number of learners reached by the provision of psychosocial supports by the DSD was not available and the Department noted that this remains a significant challenge. Prevalence of mental health conditions among the learners served by DSD is also unclear. The implementation of the ISHP has been hindered by the lack of resources and a lack of technical capacity. Norms and standards for the provision of these services to learners are due to be finalised in the 2018/19 financial year. DSD supports stigma reduction activities of the SAFMH, as well as supporting social worker posts in CBO settings. 3,852 social worker posts are subsidised in this manner, while 39 are employed directly by the Department. The DSD employs 8,664 social workers in the provinces and 3,852 posts are subsidized.

# **National Treasury**

According to National Treasury, spending on public mental health is difficult to quantify as expenditure is embedded in PHC services. Psychiatric hospital spending is easier to identify and Treasury estimated this at R5 billion per annum. A study commissioned on PHC estimated spending on mental health in this sector to be approximately R1 billion per annum. The department noted that this may be an under-estimate, but recognised that even if this was the case, mental health was likely to be significantly under-resourced given prevalence figures. As a whole, health expenditure has grown by 10.9% a year on average from R60 billion in 2006/7 to R223 billion in 2019/20, representing 13.5% of government's non-interest budget.

In psychiatric facilities, there was a significant discrepancy in funding between provinces, with the Western Cape receiving more than ten times the funding received by Mpumalanga on a per capita basis. The number of psychologists and vocational counsellors employed by government has more than doubled, although this figure totals 723 out of the 18,750 currently on the register. The current system largely decentralises health budgeting to provincial level, with provinces receiving funds according to Treasury's provincial equitable share formula. Services are a mixture of integrated and specialised services.

Treasury suggested that the strengthening of community mental health services would be key moving forward. This necessarily means increasing HRH in community facilities. While norms and standards have been developed, they remain unimplemented in many cases. The department noted that a comprehensive study was needed to examine how mental health was being funded and to identify gaps. Emerging NHI funding streams could be channelled to support pilot initiatives and develop best practice models for community-based mental health services. Treasury highlighted the (internationally funded) PRIME project as one such potential best practice model.

The department noted that increasing funding for mental health at the expense of other social programming may be counter-productive. Thus, a holistic model would be needed, and drawing on the private sector would be necessary as there remain significant resource gaps in the public sector. Improved contracting and oversight with regard to NGOs and CBOs was also necessary. A key consideration is the balance required between 'severe' and 'common' mental conditions, and this requires careful consideration of evidence, proceeding on the basis of equity in access and maximising the quality of care. Maternal mental health and improved child mental health care should be treated as priorities, based on research. Treasury did not, however, suggest that increased funding would be dedicated to these areas.

Treasury referred to a 'need for a national investment case for mental health', to identify the most cost-effective mix of interventions for mental health. Currently, such an initiative is being undertaken by the Alan J. Flisher Centre for Public Mental Health at the University of Cape Town. It also noted that inclusion of mental health in some of the emerging NHI financing streams would be looked at. The department highlighted the need for better data collection, stating that the 'data on mental health services in DHIS is not of adequate quality'. Another recommendation made by Treasury was to consider legislative or regulatory changes to the list of chronic conditions covered by Prescribed Minimum Benefits (PMB) in the regulations to the Medical

Schemes Act, No. 131 of 1998. Expanding this list would have the effect of making it mandatory for private medical aid schemes to cover pharmaceutical treatment for those conditions.

# National Department of Basic Education (DBE)

The department noted that 30,000 teachers and officials had been trained in the SIAS methodology, and that full implementation was anticipated in 2019. The introduction of the Learning Programme and Policy for Learners with Severe to Profound Intellectual Disability through the Conditional Grant in 2017 to 2020 will provide access to public funded basic education for about 20 000 learners in care centres. Within this grant an additional 155 specialists will be appointed in transversal itinerant teams in districts to provide outreach services to care centres in deep rural areas.

The DBE reported that it was engaging educators to raise awareness of risks such as depression and suicide and provision of support for learners. However, it did not provide any information regarding the incidence of depression and suicide or the evidence of these interventions. With regard to addressing stigma, the DBE noted that the SIAS framework encourages integration and support of learners with psychosocial and intellectual disabilities, but that some learners with severe or profound disabilities would require transfer to specialised centres. Statistics in this regard were not provided and no other stigma reduction interventions were reported.

The National Strategy for Learner Attainment (NSLA) requires regular reporting by provincial education departments, including reporting related to support provision to learners with psychosocial disabilities. The DBE reported that it utilises this information to analyse progress made by provincial departments, although it did not provide such an analysis. The DBE also stated that special schools will receive additional non-teaching support staff to 'ensure the safety and dignity of learners with severe disabilities in special school hostels', with a budget from 2018 to 2021 of R9,031,157,000.

# National Department of Planning, Monitoring and Evaluation (DPME)

The department's submission states that 'monitoring by the DPME focuses on aggregated service delivery data, while specific patient-based services with special emphasis on clinical outcomes arising from patient care are monitored by the health sector'. As part of the DPME's monitoring of progress towards the National Development Plan 2030 (NDP), the DPME has collected data regarding the number of people screened and treated for 'mental disorders', using the DHIS system. The department stated that, in the 2015/2016 financial year, 4,085,578 users of public health services had been screened for 'mental disorders' and 2,226,768 had been treated for same.

The DPME's submission highlighted some specific concerns relating to the inequitable distribution of HRH, particularly between the public and private sectors. In addition, the department noted that an implementation evaluation study may be required to assess rollout of the NMHPF. A similar study illustrated that South Africa's substance abuse response requires strengthening, including improved funding; research to accurately state the scale of the problem; and a new National Drug Master Plan.

Patient-level clinical data are not yet collected across South Africa, although development of the Health Patient Registration System (HPRS) by the NDOH is underway. The DPME noted that resource constraints were hampering the implementation of this system and that adequate resourcing would ensure that patient-level data would be available in a consistent and comprehensive manner. The department also reiterated the role of the Office of Health Standards and Compliance (OHSC) as a key stakeholder in monitoring health service delivery.

# National Department of Justice and Constitutional Development (DOJCD)

The DOJCD highlighted the fact that it had initiated an audit of national legislation to assess for compliance with the CRPD. The audit resulted in a recommendation that stand-alone legislation relating to the rights of persons with disabilities was needed. The DOJCD has indicated that the process for referring this matter to the South African Law Reform Commission (SALRC) has already commenced. A report by the SALRC on 'Assisted Decision-making' was also finalised by the SALRC and this report is currently awaiting the review of the Minister of Justice and Correctional Services.

The DOJCD outlined that some measures it had instituted to ensure that people with psychosocial and intellectual disabilities would be supported in approaching the courts, but also noted that codification of a policy regarding access to courts for people with disabilities had not yet occurred. The department acknowledged that further attention needed to be paid to training of court officials on the needs of witnesses, complainants and accused persons with disabilities as Justice College had not yet developed specific training modules on this subject. Regarding legal capacity issues, the department continues to train officials on legal capacity using measures such as the Criminal Procedures Act, No. 51 of 1977, the MHCA and psychiatric and psychological assessments rather than a universal legal capacity approach.

In respect of assessment procedures for accused persons, the DOJCD drew a distinction between 'mental illness' as evaluated by a psychiatrist and a 'mental disability', as assessed by a clinical psychologist. It noted that delays were a challenge, as was the securing of funding for private practitioners to carry out assessments, although it has sought additional funding to address this need.

# **National Department of Correctional Services (DCS)**

The Department noted that, in 2017, there were 4,304 MHCUs within the correctional system. There is currently a draft National Policy on Mental Health Care in the Prison System being considered for approval by the Minister. DCS does have a policy for screening for psychosocial and intellectual disabilities upon admission to a correctional facility, and noted that detainees found to exhibit symptoms of 'mental illness' were either treated by a visiting professional or referred to a public facility. In terms of the MHCA, remand detainees may also be referred to a health establishment for 72 hour observation, although the department did not furnish any data in this regard. It was also not clear what proportion of detainees deemed to be psychosocially or intellectually disabled were transferred to health care facilities.

# South African Police Services (SAPS)

The Honourable Mr Minister Fikile Mbalula MP as the then Minister of Police was invited by the Commission to, either in person or through an authorised representative, make submissions at the National Investigative Hearing Mental Health Care in South Africa. Several items of correspondence were sent by the Commission in that regard and numerous telephone calls were made. Notwithstanding the multiple items of correspondence sent by the Commission and an acknowledgment of receipt received from SAPS, to date, no response has been received.

# National Department of Human Settlements (DHS)

The department noted that there were no specific policy directives regarding the housing needs of people with psychosocial and intellectual disabilities. However, it did note that it was in the process of drafting a National Housing Programme for Special Housing Needs. Provincial departments are responsible for determining housing needs (using data from the DSD), including group housing needs, and allocating budgets for this

purpose (including the funding of NGOs and CBOs), although at present there is no clear guidance on how such a process should take place as there is not yet a formalised National Housing Programme.

# South African Federation for Mental Health (SAFMH)

As with the submission made to the OHO from the SAFMH, there was a clear indication that warnings and calls to action to prevent the tragedy that unfolded in the implementation of the GMHMP had been issued to, among others, the GDOH, the NDOH and the Commission. There is, therefore, a considerable need for implementation of mechanisms that can respond more effectively when such concerns are raised.

The SAFMH also noted the considerable challenges relating to the rollout of community-based mental health care, stating that, while a rights-based approach requires a shift towards deinstitutionalisation, it also requires that adequate preparation and capacitation of alternative structures is put in place. Failure to ensure the capacitation of NGOs and to adequately prepare South Africa for community-based mental health service provision can, as illustrated by the Life Esidimeni tragedy, result in further rights violations.

Among the challenges highlighted by the SAFMH was also a considerable lack of political will to treat mental health as a priority, echoing what researchers have described as a systematic 'lack of ownership'.<sup>156</sup> This under-prioritisation has the effect of leading to under-resourcing and insufficient infrastructure development, with the SAFMH citing lack of beds in psychiatric facilities (including psychiatric wards in generalist facilities) as a significant problem. Similarly, the Federation noted that there was a lack of infrastructure to support 72 hour assessments as stipulated in the MHCA. The SAFMH also reiterated the fact that child and adolescent psychiatric services remain particularly underserved.

Low staff morale was also cited as a concern, coupled with the fact that stigma continued to prevent generalist health care workers from engaging with people with psychosocial and intellectual disabilities. The SAFMH also cited a user engagement survey, which indicated that 59% of respondents had experienced medication stock outs, referring to this as a violation of the right to health care as contained in the Constitution.

Among the recommendations made in this submission were a review of the MHCA, adequate build-up of community-based serviced before deinstitutionalisation is to be implemented and improved monitoring and evaluation of mental health care services. On this latter point, the SAFMH noted that availability of accurate data and adequate record-keeping was a significant challenge. The Federation, a member of the Rural Mental Health Campaign, also urged the government to pay special attention to the needs of rural communities.

#### **Ubuntu Centre**

The Ubuntu Centre highlighted the challenge of raising concerns with officials, including the Premier of the Gauteng Province and the Commission, without a rapid response, highlighting the need to develop stronger and more efficient means of addressing concerns when they are raised.

The Ubuntu Centre also noted that the use of a biomedical model that emphasises an 'evidence-based' approach may not be contextually relevant and has also been questioned internationally. Therefore, further attention needs to be paid to indigenous solutions that are based in African knowledge and African needs.

# Rural Mental Health Campaign (RMHC)

The RMHC re-iterated concerns it had raised in its 2015 report,<sup>157</sup> noting that the challenges documented continued to impede access to mental health services for people with psychosocial and intellectual disabilities in South Africa's rural areas. Among the challenges it noted were frequent stock outs of medication and stigma and discrimination within communities and within the health care system, thus discouraging MHCUs from accessing services. A lack of community-based health care resulted in a 'revolving door' for MHCUs at psychiatric facilities. The RMHC recommended that community-based rehabilitation was needed to ensure that people with psychosocial and intellectual disabilities in rural areas could live fruitful lives in their communities.

# South African Society of Psychiatrists (SASOP)

SASOP reported that, nationally, there was a severe shortage of psychiatrists, and there was 'no or poorly resourced' community-based care for people with psychosocial and intellectual disabilities. In addition, it noted governance challenges that included 'dysfunctional or absent' Mental Health Directorates and MHRBs. The shortage of child and adolescent services was also highlighted.

In the Eastern Cape, SASOP noted that it had relayed its concerns to the national and provincial departments of health, including regarding the shortage of forensic facilities and the complete lack of child and adolescent facilities. In 2016, a MHCU was transferred from Limpopo province to the Eastern Cape after stabbing and killing a nurse at Hayani Hospital. SASOP quoted the Minister of Health as stating that Fort England hospital in the Eastern Cape was the only facility that could accommodate 'patients who murder'. This, according to SASOP is not the case, but it highlights the fact that forensic psychiatry facilities require greater attention from NDOH.

In the Free State, SASOP described a shortage of acute care facilities, including for children and adolescents and a provincial directorate that did not interact with clinicians. Progress was reported in KwaZulu-Natal, where vacancies had been filled and 27 newly accredited facilities were reported. According to SASOP, every district in the province also had a MHRB. SASOP also reported challenges, however, including the lack of functioning user forums, 'non-existent' community mental health services, shortages of specialists (less than 50% of posts filled) and a shortage of forensic beds, leading to delays in court cases. According to SASOP, in KwaZulu-Natal, there are 'no child and adolescent psychiatric facilities'.

SASOP noted that, in Limpopo, there is usually one (public mental health) psychiatrist in each district; thus services are extremely overstretched. Lack of retention of staff is a problem in the province, and the lack of forensic facilities was confirmed. It further stated that 'a patient died in Thabamoopo Hospital in 2016 through hanging...no specific action was instituted'. Two districts did not have a MHRB, and the province lacked a mental health directorate. Child and adolescent facilities were completely absent.

In Gauteng, the need for advocacy and awareness-raising was highlighted, as were shortages of human resources and issues relating to conditions of employment that may affect service delivery. In the Western Cape, access to medication was cited as a challenge, along with 'inadequate resourcing of child and adolescent services' and the 'near absence of resources to deal with substance abuse'. SASOP also noted an 'extreme lack of capacity at the DSD, severely undermining efforts at ... promotion of mental health' and the 'dysfunctional SAPS and Justice system resulting in more and more high-risk cases being admitted to psychiatric units instead of going through the justice system'.

# **Deinstitutionalisation Task Team (DTT)**

The DTT was convened to implement Recommendation 16 of the OHO's report, which states the following:

This investigation has clearly shown that for deinstitutionalisation to be undertaken properly, the primary and specialist multidisciplinary teams that are community-based mental health care services must be focused upon, must be resourced and must be developed before the process is started. It will most probably require more financial and human resource investment initially for deinstitutionalisation to take root. Sufficient budget should be allocated for the implementation.

The DTT thus highlighted the need for improved patient data collection and improved quality assurance systems that could be rolled out nationally. It also listed the human resource needs in Provincial Mental Health Directorates for deinstitutionalisation to be adequately rolled out as follows:

- a. 1x Director
- b. 1 x Technical Adviser (Clinical Specialist)
- c. 4 x Deputy Directors + 1 Assistant Director
  - IV. 1x Deputy Director and 1x Assistant Director (MHCA compliance and MHRB oversight)
  - V. Deputy Director (Specialty Programs)
  - VI. Deputy Director (Community-based mental health services)
  - VII. Deputy Director (Substance abuse)
- d. 1x Information Systems Officer and 1x Data Analyst
- e. 1x Senior Administration Officer
- f. 1 x Personal Assistant to the Director

Regarding community-based health care, the DTT noted that this required two parallel processes, one focusing on health service provision that is patient-oriented and multidisciplinary and another focusing on community integration, including outreach, vocational training and day care. The DTT also noted that human resource capacity and infrastructure remain far below targets, and suggested that these areas would require further financial inputs before deinstitutionalisation that meets the needs of people with psychosocial and intellectual disabilities can be realised.

#### **Individuals**

#### **Dr Lesley J Robertson (Community Psychiatrist)**

Dr Robertson is the Head of the Community Psychiatry Clinical Unit at Sedibeng District Health Services, a Lecturer in the Department of Psychiatry at the University of the Witwatersrand, and National Convener of the Public Sector Group of SASOP. Dr Robertson's submission highlights that defining the mental health care sector is, in and of itself, a challenge because mental health care encompasses the management of a broad range of conditions. The complex co-morbidity which exists between mental conditions and substance

use also complicates the clinical picture while society's response to a MHCU may exacerbate the illness and complicate management.

Dr Robertson submits that the most urgent problem facing people with mental illness in South Africa is access to appropriate care, treatment and rehabilitation. The overwhelming emphasis in public and private health sectors is on the hospital rather than community based care. In the public sector, these hospitals are often remote from patient's homes and have stringent criteria for admission of a patient. Further, there is no access to interventions such as family therapy or dialectical behavioural therapy at a community level. Monitoring and evaluation of care is absent in the public health sector and appears to be deficient in the private sector. Neither sector places an emphasis on patient related outcomes of care, nor provides for the prevention of relapse or recurrence. Both sectors do not seem to have a strategy for reducing the burden of disability related to mental conditions.

Key challenges identified by Dr Robertson include the following:

#### a. Unmet need amongst people living with mental illness

South Africa has already deinstitutionalized most of its severe MHCUs. However, there has been no parallel development of community-based psychiatric services to accommodate them. This means that the vast majority of people with mental conditions, including severe conditions, are now community dwelling. General hospital psychiatric beds are far below the country's norms for a deinstitutionalised mental health care system. There has been no indication from the NDOH of any planning for community-based psychiatric services to balance the deinstitutionalisation of MHCUs which has occurred over the past 20 years and the lack of general hospital beds. Further, there are no information systems for mental health monitoring or evaluation.

#### b. Primary care level: integrated mental health care

Integrated PHC is often cited by the NDOH as a means to manage community-dwelling people with severe mental conditions. There is however no national program guideline similar to that developed in respect of HIV/AIDS and / or tuberculosis to explain in detail how to implement the NMHPF in an effective manner. There are no national programme guidelines for mental health care or substance use.

Dr Robertson recommends, amongst others, that provision be made for MHCUs who are community dwelling. In order to achieve this the powers of MHRBs should be extended to the community dwelling MHCU to facilitate and ensure access to appropriate general and psychiatric care, supported housing and nursing home care where necessary. In terms of the National Mental Health Policy Framework and Strategic Plan, 2013-2020, specialist level mental health professionals should be available at community level as well as in general hospitals and at specialised institutions. Mental health care requires an allocated budget adequate to meet the burden of disability and this budget should be protected from both competing health priorities and the historical tendency to neglect vulnerable MHCUs.

#### Mr Jeremy Bayer (Counselling Psychologist)

The rights of vulnerable groups to access mental health care formed a significant part of Mr Bayer's submission to the Commission. He noted that just 1% of all psychiatric services were dedicated to the support and treatment of children and adolescents. This had the potential to result in minors being treated in adult facilities, leaving them vulnerable to abuse. Similarly, he cited 'rape culture' in universities and overall gender-based violence as a risk factor for increased mental health challenges, while the lack of care for transgender people was also highlighted. Similarly, Mr Bayer noted that a significant challenge continues to be inequity between public and private mental health care, in relation to costs of care, availability of professionals and, ultimately, access to quality service provision. Stigma and discrimination against people with psychosocial and intellectual disabilities was also cited as a considerable human rights concern.

Mr Bayer also noted the high cost to the economy of not treating mental health as a priority, stating that between R38 Billion to R52 Billion is lost to the South African economy due to 'mental illness'. He noted that substance abuse is of particular concern in South Africa, and that there was significant potential for mental health challenges to be 'cyclical' if not addressed.

Among the recommendations made by Mr Bayer include intervention in school curricula to raise awareness of mental health and to combat stigma. Anti-bullying initiatives should also be considered, along with more investment in child and adolescent mental health, including in schools themselves. Mandatory employee wellness in workplaces and increased visibility of people with psychosocial and intellectual disabilities in the media were also recommended.

#### Mr Robert Griffin (Chairperson of the Hamlet Foundation)

Mr Griffin is the father of two intellectually disabled children, as well as being the brother of a MHCU affected by the ending of subsidies at the Life Esidimeni facility and the uncle of a state patient at Weskoppies Psychiatric Hospital. Mr Griffin noted that the care provided in public mental health facilities was limited to medication and food. Patients who did not have family members who could provide clothing and hygiene accessories were forced to go without these. Grants were sometimes used by the NGOs or CBOs housing MHCUs to pay for their upkeep, without consultation of the MHCU. He recommended the provision of sheltered work programs and ongoing individual and group therapies. Further financial support for NGOs and CBOs was also encouraged. Mr Griffin also highlighted the fact that children in state-run or state-subsidised orphanages were often discharged when they reached 18 with little or no support.

#### **Mr Andrew Pietersen (Nephew of Victor Truter)**

Mr Pietersen's uncle was admitted to the Life Esidimeni facility at the age of 19 in 1967. Following the announcement of the end of state subsidisation of accommodation or MHCUs at Life Esidimeni, Mr Pietersen, a member of a committee of family members of those affected, attended a meeting with the MEC for Health for Gauteng Province and subsequently attended a march to present a memorandum to the MEC, to which no response was received.

Several meetings followed with other officials of the GDOH, in which the department's position did not change, despite news of deaths having been reported by then. A list of the NGOs to which MHCUs would be transferred was requested and not provided by the GDOH. Mr Pietersen described a chaotic process at the Life Esidimeni facility that resulted in his uncle being moved without any consent and without his family knowing his whereabouts for two months.

Following the move, Mr Pietersen found his uncle in a remote facility where he had not received medication for two weeks and where he was poorly fed and maintained. He described two wounds on his uncle's body and extreme loss of weight. The family committee had continued to engage with the GDOH, but found that, despite the reports of deaths, the Department defended its procedures during the GMHMP. At one meeting, Mr Pietersen described an incident where an official asked why he was concerned about 'whites'. Following the termination of the GMHMP, Mr Pietersen was involved in the relocation process and currently serves as a member of the MHRB.

Among the recommendations made by Mr Pietersen are a Presidential apology; a commemorative headstone to honour the deceased; a state pension for those affected; transportation for family members of MHCUs moved to NGOs and CBOs; and the provision of counselling for the families of those affected by the GMHMP.

#### Ms Laura Taylor (Sister of late Stephanie Anne Taylor)

Ms Taylor described the circumstances relating to the death of her sister. She had been a chronic MHCU at Weskoppies Hospital until that hospital ceased to provide chronic care. She was then transferred to a facility in Bloemfontein, where she resided for three years, until her death, the cause of which has been reported as an electrolyte imbalance, although Ms Taylor has reason to suspect that her sister may have died from pneumonia. She described extreme loss of weight and various health challenges that she noticed in her sister prior to her death. Ms Taylor wished to highlight that, while the Esidimeni tragedy took place in Gauteng and this had resulted in significant media attention directed towards the challenges in that province, 'this is happening all across the country'.

#### Ms Anna-Mari Pieterse (Country Coordinator for Humanity's Team South Africa)

Ms Pieterse's adult son had been prescribed psychotropic medication following a psychotic episode. She described his behaviour as 'suspicious and aggressive' after he started taking the medication. She noted that her son had twice 'almost died' due to the medication prescribed and decried the state of MHCUs in psychiatric facilities, noting that psychiatry had resulted in vulnerable people being exploited and abused. Ms Pieterse emphasised the 'lie of chemical imbalance' upon which psychiatry is based and encouraged the use of alternative approaches such as peer support networks to enhance the lived experiences of people with psychosocial and intellectual disabilities.

# Dr Charlotte Capri, Dr Brian Watermeyer, Prof. Judith McKenzie and Dr Ockert Coetzee (University of Cape Town)

These authors submitted that the circumstances of people with intellectual disabilities were particularly precarious in South Africa, stating that:

Countless Esidimenis are happening right now to people who are still alive, but the extent of neglectful and abusive care will again only come to light once they also die of starvation, dehydration, cold, and infection.

They noted that half of those who died during the GMHMP were living with intellectual disabilities and asserted that a distinction needed to be made between psychosocial disabilities and intellectual disabilities. They further noted that the MHCA and its General Regulation Amendment lacks rights governance for adults with any level of intellectual disability in community settings, stating that there needed to be greater emphasis on lived experiences rather than 'measuring tragedy in deaths'.

The situation of people with intellectual disabilities may require an approach that is substantively different from the measures taken in the broader mental health care system. Nonetheless, many of the recommendations are similar, including a broader, multidisciplinary approach to community-based support and an approach that maximises the participation of those affected in decision-making. In addition, the authors submitted that a 'Vulnerable Adults Act' be incorporated into South African law, to protect adults who may require safeguards that have proven to be 'inadequate' in the MHCA. Additionally, human resource concerns were also raised, with a need to need to ensure adequate, accessible, quality services highlighted.

# 6.

# FINDINGS IN FULL

t is clear, from the secondary sources consulted as well as the submissions provided to the Commission, that considerable challenges still remain in realising a rights-based approach to mental health in South Africa. Below are the findings of the Commission's investigation.

- 1. The numerous human rights concerns that have been highlighted in this investigation can be said to arise out of a prolonged and systemic neglect of mental health at the level of policy and resource allocation. Throughout the investigation, lack of resourcing, lack of technical capacity and possibly even lack of concern for the welfare of people with intellectual and psychosocial disabilities have arisen as root causes for system-wide failures to protect and promote the rights of this group.
- Inter-departmental collaboration and knowledge sharing in the realm of mental health care and service
  provision is extremely problematic and demonstrates that further attention needs to be paid to measures
  to integrate services, to improve engagement and to pool resources. Ministers in departments such
  as the NDOH, the DSD and the DBE, among others, should ensure that collaboration is fostered for
  effective governance that is rights affirming.
- 3. There is reason to suggest that the state's handling of mental health cannot be said to be reasonable in terms of the Constitutional Court's standard-setting insofar as the progressive realisation of economic and social rights is concerned. A particularly vulnerable and marginalised group's inclusion in policy and resource allocation is a necessary condition for the state's actions to be considered reasonable. In this instance, such inclusion has not adequately taken place.
- 4. South Africa requires substantial progress to be made on numerous fronts in order for the country to meet its obligations in terms of the CRPD. These include on the legislative front, where national disability rights legislation has been recommended; on awareness-raising of the rights of people with intellectual and psychosocial disabilities; and on economic and social rights such as education and health care.
- 5. Effective implementation of a rights-based approach to mental health requires an emphasis on the social determinants of mental health and well-being. This means engaging with various stakeholders to consider ways in which effective participation and inclusion of people with psychosocial and intellectual disabilities can be realised, examining barriers to social, cultural and economic inclusion and considering ways in which these forms of exclusion impede human rights and negatively impact on mental health.
- 6. Significant stigma and discrimination against people with intellectual and psychosocial disabilities persists in South Africa. Therefore, the consistent under-prioritisation of mental health care should be viewed in the broader context of a society where stigma and discrimination against people with intellectual and psychosocial disabilities results in marginalisation and exclusion from communities. Political neglect is a form of stigmatisation in its own right and requires urgent and concerted intervention to prevent further rights violations. The DTT notes, for example, that technical capacity in provincial health departments requires significant scaling up for the process of deinstitutionalisation to be undertaken. This is, ultimately, a question of political will, a factor which is inherently affected by the knowledge, attitudes and beliefs of political actors.
- 7. Stigma and discrimination in communities, health facilities, schools and institutions of higher education is a significant barrier to inclusion of people with intellectual and psychosocial disabilities. The investigation suggests that, while the state recognises this as a major challenge and has undertaken to combat this

phenomenon, there is a considerable need to actively ensure that stigma reduction programming is carried out and supported to the fullest extent. This has, thus far, not been the case.

- 8. The largest proportion of mental health budgets and the largest allocation of mental health professionals continues to be in psychiatric facilities. This is despite the introduction of the CRPD and the NMHPF, suggesting that major shifts towards community-based care are needed over time. It further suggests that a biomedical approach continues to dominate in the South African mental health care landscape. While psychiatric facilities do play an important role in the provision of health care services, the slow shifts in policy and resource allocation to support community-based service provision suggest that the state is not making sufficient strides in the adoption of a rights-based approach to mental health care.
- 9. Deinstitutionalisation is a central component of a rights-based approach to mental health care. The lack of policies in place at provincial government levels to regulate these processes is therefore concerning. Moreover, the GMHMP has illustrated the fact that deinstitutionalisation is a process that requires numerous interventions in various sectors to actualise the rights of people with intellectual and psychosocial disabilities. The GMHMP has highlighted that the model of deinstitutionalisation adopted by the GDOH was not in keeping with a rights-based approach to mental health care and did not undertake interventions to support their well-being in community-based settings. Haphazard licensure of NGOs and lack of consultation with MHCUs and their caregivers are further evidence in support of this finding.
- 10. As already noted, there is considerable under-investment in mental health by the government. The NMHPF states that 'mental health care services should have parity with general health services'. This is clearly not being realised. Considering the numerous demands placed on South Africa's health system, a budgeting approach that takes into account prevalence but also considers the broader communities in which people with psychosocial and intellectual disabilities live and inputs from other departments must be adopted to achieve a holistic and inclusive service package, including housing. Particular attention should be paid to rural communities to ensure that budgets are not concentrated in urban areas and directed at psychiatric facilities only.
- 11. While provincial departments of health carry the competency to allocate resources and deliver services, the NDOH has an oversight, monitoring and policy role that was not sufficiently developed to support provinces on subjects that included budgeting for mental health and the rights-based approach, mandated by the CRPD. There is therefore, considerable scope for expanding this oversight and capacitation role.
- 12. Provincial departments, and the local governments they work with, have not made substantial progress on implementing the provisions of the NMHPF, and have consistently failed to allocate sufficient resources for the provision of mental health services. The disparate state of budgets across provinces and the lack of costed and budgeted strategic plans in most provinces is a major concern. Similarly, the fact that most provinces still lack functioning mental health directorates calls into question the ability of provincial departments of health to carry out their mandates effectively.
- 13. Participation of MHCUs in their treatment is a central component of a rights-based approach to mental health care. However, the slow pace of instituting structures such

as stakeholder forums and the fact that the empowerment modules implemented by the SAFMH have only reached four provinces thus far is noted with concern.

- 14. The health care system us plagued by stock outs of medicines in most provinces. Stock outs of medications for MHCUs are a violation of the right to the highest attainable standard of health care. The fact these problems have persisted despite the issue being raised repeatedly by the Commission and civil society actors is cause for concern, particularly as the implications for MHCUs of not receiving medication can be extremely detrimental.
- 15. Acknowledging that there have been efforts to integrate mental health data capturing into standardised administrative systems such as the DHIS and the HPRS, the nature of the data being captured is insufficient to assess the quality of care, to monitor progress in the overall well-being and dignity of an MHCU and to inform policy and practice. This will require rectification if the government is to truly implement a rights-based approach to mental health.
- 16. HRH are a major consideration in efforts to advance the right to the highest attainable standard of physical and mental health. It is clear that inequitable availability and distribution of HRH is a major impediment to access to mental health care, particularly in rural South Africa. The state has made some progress in seeking to improve this situation, but efforts to embrace best practice, including 'task-sharing' models and peer support initiatives that emphasise the role of people with psychosocial and intellectual disabilities themselves are still required. Training of the CHWs that do exist was also noted as being inadequate and in need of standardisation.
- 17. With regard to rural areas, particular challenges have been noted in respect of barriers such as lack of infrastructure, lack of HRH, stigmatisation of people with psychosocial and intellectual disabilities and medication stock outs. Addressing these challenges in rural settings will require an approach that is markedly different to other parts of the country. The infrastructure includes roads and viable transport systems for patients to enable them to easily travel to centres where they can get assistance.
- 18. The fact that MHRBs in various districts throughout the country are not in place or non-functioning is in direct contravention of the MHCA. These bodies are intended to be accountability mechanisms that provide recourse to MHCUs and prevent abuses of power in mental health establishments. The fact that they remain non-functioning is therefore, a major concern for the SAHRC.
- 19. The limited role of the MHRBs is also a cause for concern, MHRBs also have a role to play in ensuring that community-based MHCUs receive adequate medical and psychiatric attention outside of a hospital.
- 20. Broader conversations about law reform of instruments such as the MHCA and the Electoral Act are also required in light of their potential contravention of the CRPD and in light of ongoing debates regarding matters such as legal capacity.
- 21. The lack of accurate data regarding the provision of services and supports to be people with psychosocial disabilities by the DSD is of significant concern. This makes it impossible to examine progress or to provide a basis for rectifying missteps, and need to be addressed urgently.
- 22. The right to access to justice for people with psychosocial and intellectual disabilities is placed in jeopardy by the lack of a policy regarding access to courts and by delays within the justice system and lack of specialised staff to support their participation.
- 23. An important consideration in the South African context is the right to access to health care that does not discriminate on the basis of language, cultural and religious beliefs. Further consideration by the Department of Health of the role of traditional practitioners in the mental health care system is therefore, required. Similarly, the availability of language appropriate services should be treated as a priority, with current practices suggesting that this is not the case.

- 24. There is an urgent need to address the needs of children and adolescents with intellectual and psychosocial disabilities. Almost all provincial departments reported that their provinces do not have facilities for accommodating child and adolescent MHCUs and that they are accommodated in adult wards which places them at risk for abuse. While mental health overall is a neglected area, this particular sub-field is especially under-prioritised, with the result that violations of the rights of this group are perpetrated regularly in the form of cruel, degrading and inhumane treatment. South Africa is in direct contravention of the Constitution and the CRC in this regard. The rollout of the ISHP is an important step, but high numbers of children with disabilities not enrolled in school and the shortage of beds in existing facilities specifically for children and adolescents with intellectual and psychosocial disabilities remain a concern. A rights-based approach would suggest that the mere adding of these beds would be insufficient, however, as more needs to be done to integrate these affected persons into their communities and to provide appropriate community-based services, using hospitalisation only as a last resort. It will be essential to develop community-based rehabilitation and psycho-social rehabilitation services to implement the integration of children and adolescents into their communities. This is likely to require dedicated rehabilitation staff which are available even in rural areas.
- 25. The state of mental health services in the criminal justice, forensic and correctional systems in South Africa is especially poor. It is clear that rights violations have occurred in several instances. The incarceration in prisons of 'state patients' and ongoing challenges within the criminal justice system of securing supports for survivors of sexual violence and people with psychosocial and intellectual disabilities are examples of this reality. Likewise, rates of suicide in prison are plainly unacceptable and this will require urgent intervention.
- 26. With regard to the GMHMP, the fact that warnings and pleas for assistance by civil society actors to state actors, the courts and the Commission did not result in action to prevent the unnecessary deaths of over 100 people highlights the need for rapid responses when potential human rights abuses are suspected.
- 27. The private mental health care sector could play a significant role in advancing the right to the highest attainable standard of physical and mental health. The fact that over 80% of the country's practitioners work in the private sector suggests that solutions to the shortages of HRH might be found through inter-sectoral collaboration. The NHI shows promise in this regard, but there remains a need for dialogue with private mental health care practitioners, private medical schemes and health care corporations on solutions to advance the right to the highest attainable standard of physical and mental health.

# **7.**

# RECOMMENDATIONS

# **National Department of Health**

- I. NDOH should organize a meeting with all key stakeholders involved in mental health including Health, Social Development, Education, Housing, Corrections, Treasury and Labour to establish an interdepartmental standing committee on mental health that meets at least on a quarterly basis if not more frequently. Membership of the standing committee must include MHCUs and representatives of MHCU advocacy groups. The work of the standing committee should include: developing a detailed national program guideline that sets out how the NMHPF must be implemented in an effective manner, monitoring the implementation of the NMHPF; identifying and addressing barriers to progress in the implementation of the NMHPF; engaging with relevant stakeholders to address the social determinants of mental health; extending the role of the MHRBs to include ensuring that community-based MHCUs receive adequate medical and psychiatric attention outside of hospital; drafting a post-2020 follow up policy to the NMHPF; and what revisions to the MHCA are to be contemplated in light of the NHI. Timeline: within 3 months of issuing this report.
- II. NDOH should appoint a permanent advisory body within the department whose role it is to monitor the observance of human rights in mental health service provision. This body should have a direct monitoring relationship with provincial mental health directorates, clarifying any challenges in reporting lines being confused, and special consideration should be given to the right to participation of MHCUs. NDOH must ensure that any reports of human rights violations reported by a MHRB be submitted by the provincial mental health directorates to this body. The body must maintain a record of all such reports and monitor the implementation of remedial action taken at the provincial level to address the concerns raised in the reports to ensure that any such violations are addressed timeously. *Timeline: within 3 months of issuing this report.*
- III. **Establish a more comprehensive mental health information system.** Consider disorder specific indicators that focus on screening, treatment, caseloads, admission rates, and readmission rates, and mortality rates for all priority disorders outlined in the NMHPF. Develop quality of care indicators of mental health service provision standards that can reasonably be captured in the DHIS. Such indicators should consider the advancement of the rights of persons with psychosocial and intellectual disabilities in terms of community participation, experience of stigma and self-reported mental health status. *Timeline: within 24 months of issuing this report.*
- IV. Assess the public mental health system's ability to cater to the needs of children and adolescents with psychosocial disabilities. Such an assessment should detail the exact number of minors considered MHCUs and exact information regarding children and adolescents in psychiatric institutions (including those housed in adult wards) as well as the number of children and adolescents identified as having a mental condition and/or emotional, psychological or behavioural problems. Where gaps are highlighted, plans for addressing these gaps must ensure that:\_children and adolescents with intellectual and psychosocial disabilities and mental conditions are no longer admitted to adult wards; and oversee systemic changes to current health infrastructure to guarantee the availability of community-based child and adolescent mental health services managed by stakeholders that include their caregivers, school and community.\_Timeline: within 9 months of issuing this report.

# V. Utilise its oversight, policy-making, monitoring and supportive competencies to assist provinces in implementing the NMHPF. This includes:

- a. Providing resource allocation guidelines that complement the NDOH Standard Treatment Guidelines for provincial partners to develop and implement province specific mental health plans including minimum resource allocation for mental health services as part of the health care budget. Such guidelines should include 'pathways to care' and contemplate mechanisms through which monies budgeted for mental health services may be ring-fenced or otherwise restricted for use for that particular purpose. The guidelines must also include measures aimed at ensuring that allocated budgets reach rural communities and are not concentrated in urban areas and directed at psychiatric facilities only. *Timeline: within 4 months of issuing this report.*
- b. Providing guidelines for supporting provinces to include in their mental health care plans detailed and feasible costing and budgets to match the implementation plans. These guidelines should consider the parity principle outlined in NMHPF and, where deviations from the parity principle are recommended, a reasonable evidence-based justification should be provided. *Timeline: within 4 months of issuing this report.*
- c. Finalise a national monitoring plan to assess each province and each district's progress with the NMHPF annually. The plan should include a costed and dedicated budget for this purpose. The plan should include indicators to determine the extent of improvement in progressive realisation of community-based mental health care services, taking into consideration factors such as the proportion of the mental health budget spent for community-based services, the growth of said budget, growth in capacity in terms of HRH and CHWs at the primary care level and training conducted in APC. Indicators should map expanded provincial access to rural and urban mental health care services for both adults and children. *Timeline: within 12 months of issuing this report*.
- d. Develop and implement a strategy to ensure no stock outs of medication for people living with a mental condition occur. This strategy should include MHCUs based in each province who can assist with monitoring stock outs. *Timeline: within 12 months of issuing this report.*
- e. Provide support to provincial departments of health to implement the recommendations in this Report. Including, but not limited to, assistance and support aimed at establishing a provincial mental health directorates and developing provincial strategic plans for mental health. *Timeline: Ongoing*.
- VI. With respect to the development of human resource capacity:
  - a. develop a plan for the capacitation of all members of provincial mental health directorates and DMHTs on the human rights of MHCUs. Timeline for development of plan: within 12 months of issuing this report. Timeline for implementation of plan: within 36 months of issuing this report;
  - b. finalise and implement the mental health module of the APC guidelines for task sharing mental health services including guidelines for training and supervision of the various cadres of health workers (including doctors/nurses/CHWs). *Timeline: within 6 months of issuing this report.*

- VII. In consultation with the DCS, ensure that no 'state patients' (people declared unfit to stand trial or found not to be criminally responsible for their actions by a court) are being housed in correctional facilities. *Timeline: within 12 months of issuing of this report.*
- VIII.Conduct an audit of forensic psychiatric observation facilities across South Africa. The audit report must be published and otherwise made publically available. *Timeline: within 18 months of issuing this report.*<sup>158</sup>
- IX. The Commission requires a report from the Minister of Health, detailing progress on the recommendations outlined above. *Timeline: within 6 months of issuing this report and at 6 month intervals thereafter.*

# **Eastern Cape Department of Health**

- I. In terms of implementing the NMHPF it is recommended that the Eastern Cape Department of Health, with the support of NDOH if required:
  - a. Fully staff the provincial mental health directorate in the province. *Timeline: within 6 months of issuing this report;*
  - b. Develop a plan and timeline to ensure the institution of DMHTs in all districts in accordance with the requirements of the NMHPF. *Timeline: within 24 months of issuing this report;*
  - c. Finalise the provincial strategic plan for mental health, including costing and budgeting (ensuring that it meets the criteria for minimum resource allocation). This plan should include DMHTs, community-based mental health care, the MHRBs and child and adolescent mental health services as cost centres. In addition, the plan should specifically highlight how the province will address the unavailability of psychiatric beds and what measures will be put into place to improve access to mental health care in rural parts of the province. *Timeline: within 12 months of issuing this report;*
  - d. Fully staff and provide training on the CRPD to all of the province's MHRBs; *Timeline: within 12 months of issuing this report;*
  - e. Establish inter-sectoral forums in all districts as per the NMHPF (including biannual meetings). Timeline: within 12 months of issuing this report; and
  - f. Ensure that any report of a human rights violation reported or recorded by a MHRB be submitted to the Eastern Cape Department of Health, the provincial mental health directorate, and to the NDOH. The Eastern Cape Department of Health must maintain a provincial database of such reports and ensure that the provincial mental health directorate monitors any investigation that flows from such a report and the implementation of any remedial action taken to ensure that any such violations are addressed. *Timeline: within 12 months of issuing this report.*
- II. In consultation with the NDOH, develop a plan for the revitalisation of forensic and non-forensic mental health infrastructure\_which have been historically under-prioritised. Including details on budget and specific measures taken to realise a rights-based approach. *Timeline: within 12 months of issuing this report.*
- III. The Commission requires a report from the MEC for Health, detailing progress on the recommendations outlined above. *Timeline: within 12 months of issuing this report and at 6 month intervals thereafter.*

The quality of data used to develop the indicators that form the basis of planning and performance assessment in all three spheres of government is a concern for the Commission. Therefore, where necessary, the NdoH is encouraged to collaborate with Statistics South Africa (Stats SA), as the agency responsible for the collection and dissemination of official statistics, in the execution of this recommendation. Stats SA because has a central role to play in the evaluation and improvement of data quality.

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# Free State Department of Health

- I. In terms of implementing the NMHPF it is recommended that the Free State Department of Health, with the support of the NDOH if required:
  - a. Establish and fully staff the provincial mental health directorate in the province. *Timeline: within 6 months of issuing this report;*
  - b. Develop a plan and timeline to ensure the institution of DMHTs in all districts in accordance with the requirements of NMHPF. *Timeline: within 24 months of issuing this report;*
  - c. Finalise the provincial strategic plan for mental health, including costing and budgeting (ensuring that it meets the criteria for minimum resource allocation). This plan should include DMHTs, community-based mental health care, the MHRBs and child and adolescent mental health services as cost centres. In addition, the plan should specifically highlight how the province will address the unavailability of child and adolescent psychiatric beds and what measures will be put into place to improve access to mental health care in rural parts of the province. *Timeline: within 12 months of issuing this report;*
  - d. Fully staff and provide training on the CRPD to all of the province's MHRBs. *Timeline: within 12 months of issuing this report;*
  - e. Institute inter-sectoral forums in all districts as per the NMHPF (including biannual meetings). Timeline: within 12 months of issuing this report; and
  - f. Ensure that any report of a human rights violation reported or recorded by a MHRB be submitted to the Free State Department of Health, the provincial mental health directorate, and to the NDOH. The Free State Department of Health must maintain a provincial database of such reports and ensure that the provincial mental health directorate monitors any investigation that flows from such a report and the implementation of any remedial action taken to ensure that any such violations are addressed. *Timeline: within 12 months of issuing this report.*
- II. In consultation with the NDOH, develop a plan for the revitalisation of forensic and non-forensic mental health infrastructure which have been historically under-prioritised. Including details on budget and specific measures taken to realise a rights-based approach. *Timeline: within 12 months of issuing this report.*
- III. The Commission requires a report from the MEC for Health, detailing progress on the recommendations outlined above. *Timeline: within 12 months of issuing this report and at 6 month intervals thereafter.*

# **Gauteng Department of Health**

- I. In terms of implementing the NMHPF it is recommended that the Gauteng Department of Health, with support from the NDOH if required:
  - a. Develop a plan and timeline to ensure the institution of DMHTs in all districts in accordance with the requirements of the NMHPF. *Timeline: within 24 months of issuing this report.*
  - b. Undertake to include DMHTs, community-based mental health care, the MHRBs and child and adolescent mental health services as cost centres in future strategic planning and budgeting exercises. *Timeline: within 12 months of issuing this report.*
  - c. Fully staff and provide training on the CRPD to all of the province's MHRBs. *Timeline: within 12 months of issuing this report;*
  - d. Institute inter-sectoral forums in all districts as per the NMHPF (including biannual meetings). Timeline: within 12 months of issuing this report; and
  - e. Ensure that any report of a human rights violation reported or recorded by a MHRB be submitted to the Gauteng Department of Health, the provincial mental health directorate, and to the NDOH. The Gauteng Department of Health must maintain a provincial database of such reports and ensure that the provincial mental health directorate monitors any investigation that flows from such a report and the implementation of any remedial action taken to ensure that any such violations are addressed. *Timeline: within 12 months of issuing this report.*
- II. In consultation with the NDOH, develop a plan for the revitalisation of forensic and non-forensic mental health infrastructure in the province which have been historically under-prioritised. Including details on budget and specific measures taken to realise a rights-based approach. *Timeline: within 12 months of issuing this report.*
- III. The Commission requires a report from the MEC for Health, detailing progress on the recommendations outlined above. *Timeline: within 12 months of issuing this report and at 6 month intervals thereafter.*

# KwaZulu-Natal Department of Health

- I. In terms of implementing the NMHPF it is recommended that the KwaZulu-Natal Department of Health, with the support of the NDOH if required:
  - a. Develop a plan and timeline to ensure the institution of DMHTs in all districts in accordance with the requirements of the NMHPF. *Timeline: within 24 months of issuing this report.*
  - b. Finalise the provincial strategic plan for mental health, including costing and budgeting (ensuring that it meets the criteria for minimum resource allocation). This plan should include DMHTs, community-based mental health care, the MHRBs and child and adolescent mental health services as cost centres. In addition, the plan should specifically highlight how the province will address the unavailability of child and adolescent psychiatric beds and what measures will be put into place to improve access to mental health care in rural parts of the province. *Timeline: within 12 months of issuing this report.*
  - c. Fully staff and provide training on the CRPD to all of the province's MHRBs. *Timeline: within 12 months of issuing this report;*
  - d. Establish inter-sectoral forums in all districts as per the NMHPF (including biannual meetings). Timeline: within 12 months of issuing this report; and

- e. Ensure that any report of a human rights violation reported or recorded by a MHRB be submitted to the KwaZulu-Natal Department of Health, the provincial mental health directorate, and to the NDOH. The KwaZulu-Natal Department of Health must maintain a provincial database of such reports and ensure that the provincial mental health directorate monitors any investigation that flows from such a report and the implementation of any remedial action taken to ensure that any such violations are addressed. *Timeline: within 12 months of issuing this report.*
- II. In consultation with the NDOH, develop a plan for the revitalisation of forensic and non-forensic mental health infrastructure in the province which have been historically under-prioritised. Including details on budget and specific measures taken to realise a rights-based approach. *Timeline: within 12 months of issuing this report.*
- III. The Commission requires a report from the MEC for Health, detailing progress on the recommendations outlined above. *Timeline: within 12 months of issuing this report and at 6 month intervals thereafter.*

# **Limpopo Department of Health**

- I. In terms of implementing the NMHPF it is recommended that the Limpopo Department of Health, with the support of the NDOH if required:
  - a. Establish and fully staff the provincial mental health directorate in the province. *Timeline: within 6 months of issuing this report.*
  - b. Develop a plan and timeline to ensure the institution of DMHTs in all districts in accordance with the requirements of the NMHPF. *Timeline: within 24 months of issuing this report.*
  - c. Finalise the provincial strategic plan for mental health, including costing and budgeting (ensuring that it meets the criteria for minimum resource allocation). This plan should include DMHTs, community-based mental health care, the MHRBs and child and adolescent mental health services as cost centres. In addition, the plan should specifically highlight how the province will address the unavailability of child and adolescent psychiatric beds and what measures will be put into place to improve access to mental health care in rural parts of the province. *Timeline: within 12 months of issuing this report.*
  - d. Fully staff and provide training on the CRPD to all of the province's MHBs. *Timeline: within 12 months of issuing the report;*
  - e. Establish inter-sectoral forums in all districts as per the NMHPF (including biannual meetings). Timeline: within 12 months of issuing the report; and
  - f. Ensure that any report of a human rights violation reported or recorded by a MHRB be submitted to the Limpopo Department of Health, the provincial mental health directorate, and to the NDOH. The Limpopo Department of Health must maintain a provincial database of such reports and ensure that the provincial mental health directorate monitors any investigation that flows from such a report and the implementation of any remedial action taken to ensure that any such violations are addressed. *Timeline: within 12 months of issuing this report*.
- II. In consultation with the NDOH, develop a plan for the revitalisation of forensic and non-forensic mental health infrastructure in the province which has been historically under-prioritised. Including details on budget and specific measures taken to realise a rights-based approach. *Timeline: within 12 months of issuing the report.*
- III. The Commission requires a report from the MEC for Health, detailing progress on the recommendations outlined above. *Timeline: within 12 months of issuing the report and at 6 month intervals thereafter.*

# Mpumalanga Department of Health

- I. In terms of implementing the NMHPF it is recommended that the Mpumalanga Department of Health, with the support of NDOH if required:
  - a. Establish and fully staff the provincial mental health directorate in the province. *Timeline: within 6 months of issuing this report.*
  - b. Develop a plan and timeline to ensure the institution of DMHTs in all districts in accordance with the requirements of the NMHPF. *Timeline: within 12 months of issuing this report*;
  - c. Finalise the provincial strategic plan for mental health, including costing and budgeting (ensuring that it meets the criteria for minimum resource allocation). This plan should include DMHTs, community-based mental health care, the MHRBs and child and adolescent mental health services as cost centres. In addition, the plan should specifically highlight how the province will address the unavailability of child and adolescent psychiatric beds and what measures will be put into place to improve access to mental health care in rural parts of the province. *Timeline: within 12 months of issuing this report*;
  - d. Fully staff and provide training on the CRPD to all of the province's MHRBs. *Timeline: within 12 months of issuing this report*;
  - e. Establish inter-sectoral forums in all districts as per the NMHPF Including biannual meetings). Timeline: within 12 months of issuing this report; and
  - f. Ensure that any report of a human rights violation reported or recorded by a MHRB be submitted to the Mpumalanga Department of Health, the provincial mental health directorate, and to the NDOH. The Mpumalanga Department of Health must maintain a provincial database of such reports and ensure that the provincial mental health directorate monitors any investigation that flows from such a report and the implementation of any remedial action taken to ensure that any such violations are addressed. *Timeline: within 12 months of issuing this report*.
- II. In consultation with the NDOH, develop a plan for the revitalisation of forensic and non-forensic mental health infrastructure in the province which has been historically under-prioritised. Including details on budget and specific measures taken to realise a rights-based approach. *Timeline: within 12 months of issuing this report*.
- III. The Commission requires a report from the MEC for Health, detailing progress on the recommendations outlined above. *Timeline: within 12 months of issuing this report and at 6 month intervals thereafter.*

# Northern Cape Department of Health

- I. In terms of implementing the NMHPF it is recommended that the Northern Cape Department of Health, with the support of NDOH if required:
  - a. Establish and fully staff the provincial mental health directorate in the province. *Timeline: within 6 months of issuing this report*;
  - b. Develop a plan and timeline to ensure the institution of DMHTs in all districts in accordance with the requirements of the NMHPF. *Timeline: within 24 months of issuing this report*;
  - c. Finalise the provincial strategic plan for mental health, including costing and budgeting (ensuring that it meets the criteria for minimum resource allocation). This plan should include DMHTs, community-based mental health care, the MHRBs and child and adolescent mental health services

- as cost centres. In addition, the plan should specifically highlight how the province will address the unavailability of psychiatric beds and what measures will be put into place to improve access to mental health care in rural parts of the province. *Timeline: within 12 months of issuing this report*;
- d. Fully staff and provide training on the CRPD to all of the province's MHRBs. *Timeline: within 12 months of issuing this report*;
- e. Establish inter-sectoral forums in all districts as per the NMHPF (including biannual meetings). Timeline: within 12 months of issuing this report; and
- f. Ensure that any report of a human rights violation reported or recorded by a MHRB be submitted to the Northern Cape Department of Health, the provincial mental health directorate, and to the NDOH. The Northern Cape Department of Health must maintain a provincial database of such reports and ensure that the provincial mental health directorate monitors any investigation that flows from such a report and the implementation of any remedial action taken to ensure that any such violations are addressed. *Timeline: within 12 months of issuing this report.*
- II. In consultation with the NDOH, develop a plan for the revitalisation of forensic and non-forensic mental health infrastructure in the province which has been historically under-prioritised. Including details on budget and specific measures taken to realise a rights-based approach. *Timeline: within 12 months of issuing this report*.
- III. The Commission requires a report from the MEC for Health, detailing progress on the recommendations outlined above. *Timeline: within 12 months of issuing this report and at 6 month intervals thereafter.*

# North West Department of Health

- I. In terms of implementing the NMHPF it is recommended that the North West Department of Health, with the support of the NDOH if required:
  - a. Establish and fully staff the provincial mental health directorate in the province. *Timeline: within 6 months of issuing this report*;
  - b. Develop a plan and timeline to ensure the institution of DMHTs in all districts in accordance with the requirements of the NMHPF. *Timeline: within 24 months of issuing this report*;
  - c. Finalise the provincial strategic plan for mental health, including costing and budgeting (ensuring that it meets the criteria for minimum resource allocation). This plan should include DMHTs, community-based mental health care, the MHRBs and child and adolescent mental health services as cost centres. In addition, the plan should specifically highlight how the province will address the unavailability of psychiatric beds and what measures will be put into place to improve access to mental health care in rural parts of the province. *Timeline: within 12 months of issuing this report*;
  - d. Fully staff and provide training on the CRPD to all of the province's MHRBs. *Timeline: within 12 months of issuing this report*; and
  - e. Establish inter-sectoral forums in all districts as per the NMHPF (including biannual meetings). *Timeline: within 12 months of issuing this report.*
  - f. Ensure that any report of a human rights violation reported or recorded by a MHRB be submitted to the North West Department of Health, the provincial mental health directorate, and to the NDOH. The North West Department of Health must maintain a provincial database of such reports and ensure that the provincial mental health directorate monitors any investigation that flows

from such a report and the implementation of any remedial action taken to ensure that any such violations are addressed. *Timeline: within 12 months of issuing this report.* 

- II. In consultation with the NDOH, develop a plan for the revitalisation of forensic and non-forensic mental health infrastructure in the province which has been historically under-prioritised. Including details on budget and specific measures taken to realise a rights-based approach. *Timeline: within 12 months of issuing this report and at 6 month intervals thereafter.*
- III. The Commission requires a report from the MEC for Health, detailing progress on the recommendations outlined above. *Timeline: within 12 months of issuing this report and at 6 month intervals thereafter.*

# Western Cape Department of Health

- I. In terms of implementing the NMHPF it is recommended that the Western Cape Department of health, with the support of the NDOH if required:
  - a. Establish and fully staff the provincial mental health directorate (recognising the place of mental health in an integrated care model) in the province. *Timeline: within 6 months of issuing this report.*
  - b. Develop a plan and timeline to ensure the institution of DMHTs in all districts in accordance with the requirements of the NMHPF. *Timeline: within 24 months of issuing this report*;
  - c. Finalise the provincial strategic plan for mental health, including costing and budgeting (ensuring that it meets the criteria for minimum resource allocation). This plan should include DMHTs, community-based mental health care, the MHRBs and child and adolescent mental health services as cost centres. In addition, the plan should specifically highlight what measures will be put into place to improve access to mental health care in rural parts of the province. *Timeline: within 12 months of issuing this report*;
  - d. Fully staff and provide training on the CRPD to all of the province's MHRBs. *Timeline: within 12 months of issuing this report*;
  - e. Establish inter-sectoral forums in all districts as per the NMHPF (including biannual meetings). Timeline: within 12 months of issuing this report; and
  - f. Ensure that any report of a human rights violation reported or recorded by a MHRB be submitted to the Western Cape Department of Health, the provincial mental health directorate, and to the NDOH. The Western Cape Department of Health must maintain a provincial database of such reports and ensure that the provincial mental health directorate monitors any investigation that flows from such a report and the implementation of any remedial action taken to ensure that any such violations are addressed. *Timeline: within 12 months of issuing this report*.
- II. In consultation with the NDOH, develop a plan for the revitalisation of forensic and non-forensic mental health infrastructure in the province which has been historically under-prioritised. Including details on budget and specific measures taken to realise a rights-based approach.
- III. The Commission requires a report from the MEC for Health, detailing progress on the recommendations outlined above. *Timeline: within 12 months of issuing this report and at 6 month intervals thereafter.*

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# **Department of Social Development**

- I. It is recommended that the Department:
  - a. Engage with all provincial subsidiaries and develop an implementation plan for the monitoring of day-care centres and residential facilities. *Timeline: within 12 months of issuing this report*;
  - b. Develop a policy for accountability in residential and day-care facilities, including the institution of
    a monthly reporting requirement of the proceedings of user forums in all facilities. *Timeline: within*12 months of issuing this report;
  - c. Develop a plan for the collection of comprehensive and accurate disaggregated data regarding the prevalence of mental health conditions in DSD-administered facilities. *Timeline: within 12 months of issuing this report*;
  - d. Finalise norms and standards for the implementation of the ISHP together with other relevant Departments. *Timeline: within 12 months of issuing this report*;
  - e. Develop an inter-ministerial committee to specifically consider how the DSD, the DBE and the NDOH can cooperate on the provision of mental health and psychosocial support services, including but not limited, to children and adolescents. *Timeline: within 6 months of issuing this* report;
  - f. Establish and fully capacitate substance abuse centres in every province; *Timeline: within 24 months of issuing this report*; and
  - g. Engage with the SAFMH and other DPOs to evaluate current psychosocial support programming provided by the DSD and consider how this might be strengthened. *Timeline: within 24 months of issuing this report*.
- III. The Commission requires a report from the Minister of Social Development, detailing progress on the recommendations outlined above. *Timeline: within 12 months of issuing this report and at 6 month intervals thereafter.*

# **National Treasury**

It is recommended that the National Treasury consider conducting a feasibility study to examine the possibilities for establishing a dedicated conditional grant to address the system-wide challenges with respect to mental health care in South Africa. The Commission requires a report in this matter detailing any actions to be taken or reasons for inaction. *Timeline: within 12 months of issuing this report*.

# **Department of Justice and Constitutional Development**

- I. It is recommended that the DOJCD:
  - a. In cooperation with the SALRC and the DSD, begins the process of tabling national disability rights legislation aligned with the White Paper on the Rights of People with Disabilities. *Timeline:* within 6 months of issuing this report;
  - b. Begin a review of the human rights impacts of the provisions in the Electoral Act relating to people with psychosocial and intellectual disabilities, containing recommendations for action and potential reform. *Timeline: within 12 months of issuing this report*;

- c. Finalises the codification of a policy regarding access to courts for people with disabilities. Timeline: within 12 months of issuing this report; and
- d. Develop and implement a plan for the training of court officials on the needs of witnesses, complainants and accused persons with disabilities. *Timeline: within 24 months of issuing this report*;
- II. The Commission requires a report of progress which should also include details of the Minister's review of the report on Assisted Decision-Making and attempts to secure additional resources for the services of mental health professionals, detailing any actions to be taken or reasons for inaction. *Timeline: within 12 months of issuing this report and at 6 month intervals thereafter.*

# **Department of Basic Education**

- I. It is recommended that the DBE:
  - a. In conjunction with the NDOH, formulate a plan for introducing stigma reduction programming in schools and increasing access to health services (including counselling) through formal referral pathways accessible to educators. This plan should indicate: what policies will be implemented to ensure that South African schools are safe and supportive environments; how to improve the quality of relationship between teachers and learners; and how detection rates will be improved and referrals implemented in the event that a learner appears to require mental health support or services including counselling. Timeline: within 12 months of issuing this report;
  - b. In conjunction with the NDOH, formulate a plan for introducing consistent mental health awareness-raising efforts aimed at educators. The plan should indicate how educators will: provide accurate information about mental health conditions; promote mental health; assist learners to identify mental health conditions and obtain the necessary assistance; and assist learners to build skills that promote mental health and prevent suicide. *Timeline: within 12 months of issuing this report*;
  - c. Develop a report detailing progress in achieving the NSLA's goal of provision of supports for learners with disabilities. *Timeline: within 12 months of issuing this report*;
  - d. In consultation with the NDOH and the DSD, commence a study on the implementation of the ISHP's mental health programming, paying specific attention to the advancement of the right to the highest attainable standard of physical and mental health and barriers to implementation. *Timeline: within 24 months of issuing this report*; and
  - e. Advise the Commission on the progress of the Draft Policy for the Provision of Quality Education and Support to Children with Severe to Profound Intellectual Disability. *Timeline: within 3 months of issuing this report.*
- II. The Commission requires a report of progress, detailing any actions to be taken or reasons for inaction. Timeline: within 12 months of issuing this report and at 6 month intervals thereafter.

# **Department of Correctional Services**

- I. It is recommended that the DCS:
  - a. Assist the NDOH to ensure that no 'state patients' (people declared unfit to stand trial or found not to be criminally responsible for their actions by a court) are being housed in correctional facilities. *Timeline: within 12 months of issuing of this report*;
  - b. Finalise the National Policy on Mental Health Care in the Prison System, including a fully costed, budgeted plan for implementation. *Timeline: within 24 months of issuing this report*;
  - c. Conduct an independent evaluation of the screening of detainees for intellectual and psychosocial disabilities and the provision of mental health care to affected detainees. *Timeline: within 12 months of issuing of this report*; and
  - d. Conduct an inquiry into the high rates of suicide in South Africa's correctional system, specifically considering whether the provision of mental health care services (including counselling) is adequate, furnishing a report thereof upon completion of the inquiry. *Timeline: within 18 months of issuing this report*.
- II. The Commission requires a report of progress, detailing any actions to be taken or reasons for inaction. Timeline: within 12 months of issuing this report and at 6 month intervals thereafter.

#### South African Police Services

- I. The SAPS is required to address written correspondence to the Commission answering the following questions and providing the following information:
  - a. Does the SAPS have in place any training programmes that specifically aim to assist its staff in managing cases that involve MHCUs? This answer should specifically address whether any such training is aligned with or otherwise based on the CRPD and the White Paper on the Rights of People with Disabilities.
  - b. Statistical information of cases dealt with by the SAPS involving MHCUs over the last ten financial years, commencing in 2007/2008?
  - c. How does the SAPS monitor the effectiveness of its policies that aim to assist MHCUs?
  - d. What are the costs associated with the delivery of resources to support MHCUs?
  - e. What, in your view, are key challenges confronting SAPS when engaging with MHCUs?
  - f. What are your proposed recommendations to address these challenges?
  - g. In your view, what key priority areas require the allocation of more resources in order to adequately accommodate the varied needs of MHCUs by the SAPS?
  - h. What steps have the SAPS taken to ensure early identification and referral of MHCUs in terms of section 40 of the Mental Health Care Act, 2002?<sup>159</sup>
  - i. Has SAPS developed guidelines for the implementation of Section 40 of the Mental Health Care Act? If no, why not? If yes, what have been barriers to implementation of these guidelines?

<sup>159</sup> Section 40 of the Mental Health Care Act obliges the SAPS to transport a person to a health facility when he or she is judged to be a danger to himself or herself or others due to mental illness or intellectual disability.

- j. Has SAPS trained its employees to assess whether a person is a danger to himself or herself or others due to mental condition or intellectual disability?
- k. If so, what training has been undertaken and by which members of the SAPS?
- I. Has SAPS collaborated with any state departments, members of civil society, or MHCU advocacy groups in developing guidelines for early identification and the management of forensic and behaviourally disturbed clients in police custody while in transit to or awaiting hospitalisation?
- m. Any other information of relevance to SAPS' engagements with MHCUs?
- n. What is the status of the SAPS investigation into the Gauteng Mental Health Marathon Project?
- II. SAPS is requested to both answer the questions above and provide detailed supporting evidence and information to support its answers. *Timeline: within 3 months of issuing this report.*

# **Department of Human Settlements**

- I. It is recommended that the DHS:
  - a. Finalise the National Housing Programme for Special Housing Needs, including provisions for the housing needs of people with psychosocial and intellectual disabilities. *Timeline: within 12 months of issuing this report.*
  - b. Finalise a fully costed, budgeted plan for the implementation of the National Housing Programme for Special Housing Needs. *Timeline: within 24 months of issuing this report.*
- II. The Commission requires a report of progress, detailing any actions to be taken or reasons for inaction. Timeline: within 12 months of issuing this report and at 6 month intervals thereafter.

#### **Public Protector**

As noted by the report outlining progress in the implementation of the recommendations of the OHO, there have been significant outlays of funds for mental health infrastructure in the Northern Cape and North West province. Despite this, no facilities have been commissioned for use. It is therefore, recommended that the Public Protector consider an investigation into the use of public funds in this regard.

# conclusion

# 8.

# CONCLUSION

he issuance of this report is the culmination of a lengthy process in which the Commission has sought to examine a very broad range of issues, solicit input from a wide range of stakeholders and issue findings and recommendations that are far-reaching in their scope and in their intention.

The National Investigative Hearing on the Status of Mental Health Care in South Africa has illustrated that such far-reaching reforms are necessary if the principles of a rights based approach to mental health are to be operationalised and if the rights contained in the Constitution and the CRPD are to be actualised.

The recommendations provided herein are ambitious in their nature, and seek changes that are deep and have a meaningful impact on the lived experiences of those affected. This necessarily means that a great deal of work lies ahead for the government and for the many stakeholders and duty bearers mentioned in the report.

Yet the consequences of failing to adopt the needed reforms are too grave and the impact on the lives of those affected too severe for the state to ignore. South Africa has witnessed an unconscionable tragedy unfold in the form of the Gauteng Mental Health Marathon Project, but this episode has led us down a path towards reforms that can and must prevent any further loss of life and any further human rights violations.

The Commission thanks all participants in this process and remains committed to ensuring that the lived experiences of all people, regardless of ability, health status or any other ground, are characterised by dignity, equality and the pursuit of human rights and freedoms.



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