

2015

The Rural Mental Health Campaign Report

A call to action

This report sheds light on the dehumanising lack of mental health care services in rural settings and envisages a mental health care system that is accessible to people in all settings and that realises their dignity and constitutional rights.





The Rural Mental Health Campaign Report

Endorsement

The South African Society of Psychiatrists is in support of the Rural Mental Health Campaign which highlights the plight of mental health care users in rural areas. The integrity of the health care system depends on the equitable distribution of resources and this includes access to medication for all South Africans and in particular mental health care users in rural areas. The National Mental Health Policy Framework and Strategic Plan is designed to ensure the availability of medication to mental health care users in line with the national guidelines and the Essential Drug List. The South African Society of Psychiatrists recommends that the necessary steps be taken to implement The Mental Health Policy Framework in all provinces.

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The RMHC Partners



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Acknowledgements

We thank the mental health care users who shared their testimonies and the social workers from the South African Federation for Mental Health who collected their testimonies.

We acknowledge, in particular, the following participants:

- Njabulo Nene
- Dumisani Madlala
- Ngcobo Khulekani
- Sithembiso Mhlongo
- Hendry Mbhalati
- Jethro Mnambithi Mthembu
- Dumisani Jonase Mpanza
- Ongeziwe Mhlanganiso
- Jill (pseudonym opted for)
- Grace (pseudonym opted for)
- Patrick Dambuza Mashele
- Thembalihle (pseudonym opted for)

We recognise the work and commitment of the members of The Rural Mental Health Campaign Committee:

- Shannon Morgan (RuReSA) – Chairperson
- Garret Barnwell (Clinical Psychologist)
- Ingrid Daniels (Cape Mental Health)
- Meba Kanda (RuDASA)
- Charlene Mapukata (PACASA)
- Mafoko Phomane (RHAP)
- Charlene Sunkel (South African Federation for Mental Health)

In Memoriam

We honour Jethro Mnambithi Mthembu (1962–2015) who passed away at the age of 53, only a few weeks after he had contributed his testimony to the Rural Mental Health Campaign Report. We are grateful that Jethro shared his experience of accessing mental health care services, and offer our sincere condolences to his family and friends.

Credits

DTP support, Sandra Ellis, Cape Mental Health

Photographers: Shannon Morgan (rural scenes); Eric Miller Photography (service users); Michael Hattingh (advocacy protests); AHP (patients in queue picture front page); Dalton Dingelstad (clinical associate picture)

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Foreword

A call to action!

The health of persons living with mental health-related challenges has long been neglected by the public health care system in South Africa. Services offered have largely been modelled on institutional care and have lacked elements that promote social inclusion, empowerment, hope and independence. Services have been centralised in tertiary hospitals in the main cities of South Africa, while most people living with mental health-related issues in smaller towns and rural settings are confronted with unsupportive and inadequate desert-like mental health care services. The lack of mental health care services in rural settings is dehumanising.

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Acknowledging this social injustice at the National Mental Health Care Summit in 2012, the Government legitimately placed the lives of those persons living with mental health-related illnesses in the spotlight. Enthused, the Summit led to the development of a progressive and ambitious National Mental Health Policy Framework and Strategic plan 2013–2020 (hereafter referred to as the National Mental Health Policy Framework). Finally, services that affirm dignity through access, quality and adequacy were said to be a priority for the Department of Health. The commitments made by South Africa's National Department of Health in the National Mental Health Policy Framework finally brought with it the hope for positive change to the mental health care system in South Africa. Through this document the Government not only acknowledged the growing crisis in mental health care in South Africa, but also reaffirmed that access to mental health care is not a privilege but a constitutional right.

We are now two years on and, sadly, little progress has been made towards realising the objectives and activities within the plan. Expectations are high; however, timing is fragile. We now stand on the brink of two destinies that will both have drastic implications for mental health in South Africa. Dangerously, we have a chance to lose the policy gains that have been made if we do not adequately support the implementation of the National Mental Health Policy Framework. We also have the freedom to choose a more humanising destiny. Now, more than ever we should be investing ourselves in the up-scaling of mental health care services, realising the vision that has been eloquently expressed by the National Department of health in the plan. We have a constitutional obligation to ensure that those living with mental health-related illness have access to health care services in all settings and their right to dignity is realised through these actions.

This report reflects the voices of patients and health care workers. The people whom we have engaged with in the development of this campaign have laid testimony to their experiences of mental health care service in rural areas of South Africa. The report sheds light on the difficult conditions endured and brings our attention to the need to ensure that rural mental health is always considered in the up-scaling of mental health care services. Recommendations are proposed that are envisioned to create a more humanising mental health care system for people in rural settings. These proposals are in line with the Alma Ata Declaration and the National Mental Health Care Policy Framework. In this document, we are not only presented with a choice, but concrete proposals for the way forward.

Essentially, we are driven by the belief that there is no health without mental health and we must continue to fight until these services reach rural areas.

Aluta Continua

Shannon Morgan

Chairperson

The Rural Mental Health Campaign

Executive Summary

The Rural Mental Health Campaign was started in 2014 by a group of organisations at the Rural Health Conference in Worcester who were deeply concerned about the lack of progress made in the implementation of the National Mental Health Policy Framework. Through the discussions, a worrying picture was presented about the state of rural mental health care and it was decided that an organised response was needed to ensure that rural mental health is prioritised.

The South African Stress and Health (SASH) study, which was the first nationally representative epidemiological survey of common mental disorders in the country, found that the minority of South Africans living with mental disorders, one in four, have access to treatment¹. The treatment gap in low- and middle-income countries is estimated to be around 76%–85%, meaning that the majority of people with severe mental disorders in these countries receive no treatment at all².

Rural areas account for almost half the country's population but still remain the most underserved and marginalised.

This report is about the challenges that people living with mental illness face in rural areas. Rural areas account for almost half the country's population but still remain the most underserved and marginalised. Relative progress has been made on the reengineering of Primary Health Care (PHC); however, rural mental health care services are still largely inadequate. The report has found that this is due to the lack of service availability and accessibility, budgetary constraints, insufficient human resource capacity, a lack of integrated care, as well as stigma and discrimination.

The testimonies of mental health care users from rural areas in the Eastern Cape, KwaZulu-Natal, Limpopo and the North West, echo through the Rural Mental Health Campaign's findings and recommendations. The report portrays how mental health is neglected in rural settings and demonstrates why rural mental health must be prioritised. It explores how the budget for mental health care services can be mobilised to produce resources that equally benefit rural populations. The report highlights how stigma and discrimination remain significant barriers to accessing mental health care services. An assessment of the shortage of health care workers in rural areas supports the need for a human resources strategy that improves the quality of mental health care through the support of health care workers. Furthermore, the report highlights the importance of investing in community-based mental health care services in rural areas. Medication stock-outs have also been discussed as hindering a person's quality of life and their right to health and dignity.

Lastly, the report draws attention to the fact that although access to antiretrovirals has improved, the mental health consequences of people living with HIV and AIDS are poorly recognised.

Mental health care services can no longer just be an added component of the services offered at PHC level, but must be holistically integrated in all interactions with service users. If South Africa is to make a meaningful change then:

Mental health care services must be holistically integrated in all interactions with service users.

1. Provinces must ensure that the National Mental Health Policy Framework is translated into the provincial strategic and operational plans.
2. Provincial strategic and operational plans must explicitly demonstrate that the context of rural mental health care settings has been taken into account.
3. Provinces' plans must include targets, indicators, budgets and timelines that support the realisation of accessible and quality mental health care services for rural populations.
4. Provincial health departments must monitor and evaluate the implementation of the National Mental Health Policy Framework and ensure the provision of a sustainable budget for mental health services to develop the capacity of mental health departments and supporting structures.



Budgeting for Mental Health in South Africa
Daygan Eager
The Rural Health Advocacy Project (RHAP)

Budgeting for mental health in South Africa: what do we know and how can we mobilise resources for the benefit of rural communities?

Budgets are arguably one of the government's most important policy documents. In the absence of adequate funding for the implementation of activities and delivery of services, policy commitments and strategic plans – no matter how progressive they appear – are often rendered paper promises.

In this chapter we briefly discuss how mental health is dealt with in public sector health care budgets at both national and provincial levels. We start by briefly setting the scene in terms of the need for mental health care services and the economic impact of not providing these services. We then look at how mental health is (or is not) dealt with in budgets. Finally, we make some recommendations as to what the priorities for mental health and budgeting should be going forward and how a more transparent approach to budgeting for service delivery could be used to advance the right to mental health care services for rural communities.

The burden of mental disorders in South Africa

To understand the economic cost of mental disorders and get an idea of what should be invested in the treatment of these, one must first have an understanding of the prevalence of mental disorders.

The World Health Organization (WHO) estimates that mental disorders account for approximately 13% of the global burden of disease. Of those suffering with severe mental illness, up to 75% of people in low- to middle- income countries and between 35% and 50% of people in high-income countries do not receive treatment for their disorders³.

In South Africa data on prevalence is somewhat limited, but from what we do know the situation seems to be extreme. According to findings from SASH study⁴, an estimated one in six South Africans will have a mental disorder in a 12-month period and one in three will have a mental disorder at some point in their lifetime. In the same study it was estimated that only 28% of people with severe disorders and 24% of people with mild disorders receive treatment⁵.

The economic cost of mental disorders

Based on the limited statistics available, it would be fairly uncontroversial to say that globally mental health disorders are amongst the most prevalent non-communicable diseases. As with other chronic conditions, the long-term economic impact of untreated mental illness is significant. The World Economic Forum estimates that between the years 2010 and 2030 mental illness will account for approximately US\$ 16 trillion in lost Gross Domestic Product (GDP) globally, pushing millions of households further into poverty⁶.

As with burden of disease data, data on the economic impact of mental disorders in South Africa is limited. A recent study that tried to estimate economic impact based on data from the SASH study, conservatively estimates that in 2005 lost household income due to depression and anxiety disorders alone was more than US\$ 3 billion (R40 billion)⁷ or nearly 2,2 % of the GDP.

As with burden of disease data, data on the economic impact of mental disorders in South Africa is limited.

Investing in mental health care

Despite the fact that mental illness is one of the most prevalent non-communicable diseases in low- middle- and high-income countries and the economic impact is clearly significant, investment in the treatment and prevention of mental disorders is relatively insignificant.

Globally, less than US\$2 is spent per person per year on treating mental illness. In low- and high-income countries median per capita expenditure is less than US\$ 0.25 and US\$ 45 respectively.

In South Africa, there has never been any systematic tracking of expenditure on treating mental illness in either the public or private sectors, let alone between urban and rural health care contexts. The most comprehensive data available is from 2004 and was reported on as part of the WHO's country report on the outcome of the SASH⁸.

In this instance, only four of the country's nine provinces could actually report on mental health expenditure. On average, the Gauteng, North West, Mpumalanga and Northern Cape provinces each spent approximately 5% of their total health budget allocations on mental health services. Generally, the bulk of mental health expenditure was on services provided in specialised psychiatric facilities (Table 1):

Province	Proportion (%)
Gauteng	67
Mpumalanga	85
North West	99
Northern Cape	94

Table 1: Proportion of provincial mental health expenditure on mental hospitals 2007(6)

It should be noted that these figures exclude expenditure in the private sector, which is largely only accessible to 16% of the population with medical scheme coverage. Even here, where expenditure is relatively closely monitored, it is difficult to determine what is spent on mental health care. Recent figures from the country's largest medical scheme, Discovery Health, indicate that in 2012 their payments to providers for mental health care totalled as much as R494.6 million⁹. While substantial, this amount is only a portion (albeit a large one) of mental health expenditure in the private sector.

National Mental Health Policy Framework (2013–2020) and commitments to mental health care financing reforms

One of the primary reasons that it has been difficult, if not impossible, to determine what is being spent on mental health services in South Africa in general – let alone specifically in rural contexts – has been the absence of a coordinated mental health strategy that is both costed and fully funded. This could potentially change if the Department of Health (DoH) fully implements its National Mental Health Policy Framework¹⁰ which is meant to finally give some direction to the government's obligation to realise the promise of the South African Mental Health Care Act of 2002.

Even though the National Mental Health Policy Framework gives only cursory mention of rural mental health, it does provide an opportunity to advocate for and monitor expenditure on mental health care services across all levels of the health system in ways that would promote greater rural/urban equity.

Of particular importance in this regard are proposals aimed at giving mental health services greater prominence in health budgets at both national and provincial levels. The National Mental Health Policy Framework commits to ensuring that, at the national level, budgets are aligned with policy priorities and targets and calls for greater coordination between the

National Department of Health (NDoH) and provinces through regular “discussions” on policy priorities and progress towards targets.

Most critically, however, the National Mental Health Policy Framework states: “all provinces will develop provincial strategic plans for mental health in keeping with national policy, which outline specific strategies, targets, timelines, budgets and indicators in 2011 and annually thereafter” (p. 25).

So the question is what has changed since the National Mental Health Policy Framework was introduced in 2013?

Mental health budgets national level

The NDoH’s strategic plan 2014–2019 does include the strategic objective: “Improve access to mental health services” (p. 30). In this plan the national targets set for the achievement of this objective are somewhat limited and are provided as:

- Increasing from 25% of 16% (prevalence) of people screened for mental disorders in 2013/14 to 35% of 16% (prevalence) in 2018/19
- Increasing from 25% of 16% (prevalence) of people treated for mental disorders in 2013/14 to 35% of 16% in 2018/19

Beyond this there is no other publically available strategic planning documentation that demonstrates how greater prominence will be given to mental health services or how coordination with provinces in achieving these targets will take place.

The paucity of information or any indication of priority given to mental health and the implementation of the basic goals and objectives of the National Mental Health Policy Framework are reflected in the NDoH’s annual budget. Here mental health is identified as a component of the department’s response to non-communicable diseases under its PHC programme.

For 2013/14, R24 million was allocated for activities under the non-communicable diseases sub-programme, which increases to R29 million in 2017/18. The problem is that there is no indication of what is allocated to mental health or how the money will be spent. Based on this assessment there is no clear indication if at the National level any priority is given to mental health.

Mental health expenditure at the provincial level

One of the most important commitments in the National Mental Health Policy Framework is that provinces would be required to develop provincial strategic plans for mental health that contain specific strategies, activities, targets and budgets.

A perusal of publically available provincial health strategic planning documentation reveals that none of the provinces has met this commitment and there is no indication that any process is currently underway to do so.

Even within provincial health strategic plans more generally, mental health has been given little prominence. In these plans mental health is accounted for as part of non-communicable diseases with few, if any, clear strategies or targets outlined for mental health services as a component of a PHC approach.

Where mental health does receive a degree of prominence is as part of provincial hospital services where psychiatric hospitals are included as a distinct category of specialised facility. In this instance, targets are provided for admissions, bed utilisation and expenditure. While important information, these activities and targets only constitute a fraction of what could be considered a provincial mental health strategy.

The limited articulation of provincial health departments' approach to mental health contained within their strategic planning documentation is repeated within provincial health budgets. No province provides detail on mental health expenditure beyond what has been allocated to psychiatric facilities. In short, this means that the only publically available information on what is being spent on mental health care services in the public sector is for expenditure on psychiatric facilities.

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On average provinces will spend 2.9% of their total budgets on psychiatric facilities in 2015/16. If we compare expenditure across provinces (Table 2) we see that the North West Province spends the highest proportion of its budget on these facilities (4.6%) while Mpumalanga spends the least by some margin (0.37%).

Province	Provincial budget allocation (ZAR)	Expenditure Psychiatric Hospitals (ZAR)	% Provincial budgets spent on Psychiatric hospitals
Eastern Cape	18 495 913	586 360	3.17
Free State	8 675 429	292 219	3.37
Gauteng	34 175 179	1 057 859	3.10
KwaZulu-Natal	32 981 786	797 229	2.42
Limpopo	14 754 136	584 217	3.96
Mpumalanga	9 995 809	37 129	0.37
Northern Cape	4 074 388	48 376	1.19
North West	8 904 071	410 847	4.61
Western Cape	19 604 029	759 235	3.87
Total	151 660 740	4 573 471	

Table 2: Provincial health expenditure on psychiatric hospitals 2015/16

While useful in highlighting priority given to psychiatric facilities in South Africa, this budget information reveals little about the true priority given to mental health within the public health care sector. This is particularly troubling as increasing priority is given to the delivery of services at the district level as part of the government's push to give greater prominence to a PHC approach to care that prioritises health promotion and disease prevention within communities.

Conclusions and recommendations

One of the most striking points in the planning and budgeting for mental health services is that there is little clarity regarding how approaches to the financing and delivery of services differ between various contexts. It is imperative that the differences between urban and rural contexts in South Africa be taken into account when planning and budgeting.

As with other health care services in general, access to care and the provision of services are both more difficult and more expensive in rural areas. Rural areas have higher levels of economic deprivation; patients have to travel longer distances to facilities (particularly hospitals) at a significantly greater cost; and historically rural areas have suffered from neglect when it comes to investment in the development of critical health infrastructure and human resourcing¹¹.

In this report we have highlighted how, in combination, these factors make access to health care in rural areas incredibly difficult and render the efforts of the many dedicated health care workers who strive to provide that care virtually impossible. The testimonies in this report speak to the urgency of developing rural friendly mental health policies and budgets that are responsive to the context in which mental health care is provided. The question is what does this mean practically for policy makers and bureaucrats? How does what they do need to change to account for rural need?

A good start would be to re-look at mental health policies and budgets from the perspective of rural-proofing. This would require the systematic consideration of each and every element of the government's approach to mental health to determine what could be done differently to improve access to mental health care services in rural contexts.

With specific regard to budgets, rural-proofing would demand that the following issues be considered:

1. Rural mental health services and facilities must be identified and distinguished from those in urban areas. This would require 'rural' to be systematically defined. It would also require that the factors in rural contexts that make accessing mental health services more difficult (e.g. inaccessibility of specialised psychiatric care located in cities) be acknowledged and articulated during budget processes
2. The cost to provide services in rural areas and how they differ from urban contexts must be determined. That is, do proportionally larger budgets need to be allocated to rural areas to ensure that rural patients have equal access to services as those in urban areas?
3. How efficiency in service delivery can be improved to ensure that available resources are used to achieve maximum benefit for patients. This may require doing things differently and thinking creatively about how access can be improved without significantly adding to the cost of service delivery.

Without the explicit consideration of rural service delivery contexts in health budgets and strategic plans, there is little hope that rural mental health will get a fair deal. Since there has been little progress in the implementation of the National Mental Health Policy Framework generally, South Africa is still a long way off from budgeting for and implementing a mental health strategy that is rural-proofed. That said, it does have the National Mental Health Policy Framework that it can work with and a health system undergoing a process of reform in preparation for the National Health Insurance (NHI). This presents an opportunity to effectively integrate rural proofing into the planning and budgeting for rural mental health services. This undertaking is one that the Rural Mental Health Campaign can make a valuable contribution to achieving.



Stigma and Discrimination

Charlene Sunkel

South African Federation for Mental Health (SAFMH)

Stigma and Discrimination

Being free from stigma and discrimination is a basic human right.

Human rights became a global focus after the Universal Declaration of Human Rights was adopted by the UN General Assembly in 1948.

In the early 1960s deinstitutionalisation was implemented in the United States and parts of Europe, acknowledging the rights of mental health care users. South Africa implemented the same, officially in 2004 when the new Mental Health Care Act 17 of 2002 came into effect.

In 2007 South Africa became one of the first 10 signatories of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Article 5 of the UNCRPD, which deals with equality and non-discrimination, states that all signatories shall “Prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all ground”.

In its Country Report to the UNCRPD, South Africa responded to the progress made in the implementation of Article 5 on Equality and non-discrimination and states that:

It is recognised that there is a persistent disjuncture between the theoretical framework and the lack of effective implementation of such rights. So while persons with disabilities are, in principle, able to harness the law to protect and pursue interests on an equal basis with others, a number of obstacles, including persistent harmful traditional beliefs, ingrained stigmatisation and consequent discrimination on the one hand, and the interrelatedness of disability and poverty on the other, the inability to afford legal fees, lack of information in the use of equality courts, accessibility of equality courts, communication barriers, lack of a disability-sensitive judiciary and court staff, inaccessible and transport, detract from the equality provided for in law.

The report also states that:

Further compounding the lack of access to justice is the high instance of undiagnosed intellectual impairment and mental illness in impoverished and rural communities. A system to avoid wrongful criminal convictions in the absence of assessment to distinguish between intellectual disability and criminal capacity, is urgently required.

Lastly, it states that:

It is acknowledged that, as so eloquently illustrated through numerous case studies and submissions presented during the consultative process in drafting this report, that laws and policies cannot, in and of themselves, change the lives of persons with disabilities, but that it requires coordinated planning, provisioning and enforcement by Government to ensure that

persons with disabilities have access to the services that the law provides. This is particularly relevant in relation to equal access to justice for children with sensory, communication, intellectual and psychosocial disabilities from poor and/or rural households.

South Africa's National Mental Health Policy Framework emphasizes (in point 7.5 on Advocacy – p.27) that there is a commitment from the DoH to “give exposure to positive images of mental health advocates, prominent user role models and well-known and influential champions for mental health in order to change discriminatory attitudes toward mental disability. This work will be framed within the provisions of the UN Convention of the Rights of Disabled Persons and the human rights based framework of South African law, as well as advocacy guidelines from the WHO” and further states that “Emphasis will be placed on ensuring representation of people with mental disability on the broader disability agenda, and developing capacity to place mental health user concerns on the political, development and public health agenda”. These goals were set to be achieved by 2015, and it is therefore critical that all persons with mental disabilities are empowered as a matter of urgency to ensure that they are able to fully participate within the ambit of these activities and successfully achieve these goals without any further delay.

Jethro – a mental health care user from KwaZulu-Natal – confirms the gap in acknowledging mental health care users as a key partner in improving mental health care services, by stating that: *“People tend to disregard a mad person's opinions on issues of discussions”*.

At the 2012 National Mental Health Summit in Ekurhuleni, Gauteng, Minister of Health, Aaron Motsoaledi, stated that it is an offence against human rights to neglect the worst-off in society, and stressed that resources, infrastructure, social mobilisation plans and employment targets must take mental health into consideration. There is a need for an increased focus on mental health promotion, prevention programmes, public awareness and stigma and discrimination in South Africa.

Several of the mental health care users interviewed for this report pointed out that public awareness is needed in communities to eliminate stigma and discrimination. In the words of Patrick from Limpopo: *“People who do not know about the condition are judgemental ... People should be educated so that they respect you”*. This highlights the right to dignity.

Despite the advancements in human rights focussed legislation, progress made in medical science in terms of diagnosing and treating mental disorders and improved understanding of mental disorders in general, we are still stuck with stigma and related discrimination, and this fact is clearly acknowledged by our government.

Stigma involves elements of ignorance, attitude and behaviour where negative responses are directed at a certain group of society – persons with mental disorders are one of the most vulnerable among all the marginalised groups of society.

Stigma and related discrimination have a huge impact on a person's life, and cause severe disabling effects, even more so than the symptoms of their mental disorder. It creates barriers that prevent mental health care users from accessing and enjoying their constitutional rights.

Statistics indicates that 75% of people who experience symptoms of mental disorders do not access mental health care services – this is not necessarily because services are not available; it is largely because of stigma – people avoid seeking help because they fear being stigmatised and being discriminated against by society.

Stigma and related discrimination have a huge impact on a person's life, and cause severe disabling effects, even more so than the symptoms of their mental disorder.

Jill, a mental health care user in North West province clearly expressed the impact of stigma: *"I feel ashamed of my diagnosis and the severity of it ... People see mentally ill people as being mad and should be locked away in an institution"*.

A common barrier faced by mental health care users, is that of accessing employment – stigma often leads to employers being reluctant to employ a person with a mental disorder. The misperception is that persons with mental disorders are unemployable, unreliable, dangerous, unable to think or speak for themselves or make informed decisions, and are unable to be functional and productive members of society.

In another comment by Patrick, he said: *"I haven't been able to get a job even though I know I can work"*.

Stigma and discrimination is further highlighted in the following comment from Dumisani (mental health care user in Kwa-Zulu Natal): *"People do not think you can do anything good. They always see you as a person who is confused."*

How can mental health care users prove these misperception wrong and show their abilities, when no one wants to give them a chance? And how can they achieve their highest potential when stigma and discrimination stands between them and accessing mental health care services? Ultimately, how are they able to claim their right to dignity?



**“There can be no mental health for all
without health care workers”**

Dr Prinitha Pillay
Rural Health Advocacy Project (RHAP)

“There can be no mental health for all without health care workers”

State of access to care in rural areas - why healthcare workers are a much-needed resource

For those who access and work in rural health care facilities, there are certainly some markers of progress. It is also undeniable that from at least the year 2008 there has been consistent commitment to improving access to care for the most underserved populations in the country. The fact that rural patients who need antiretrovirals are increasingly able to access treatment at their nearest clinic stands testament to this. Delivery of mental health services though has not had as much success.

The reality is that as a country we are still a long way from meeting the promise and right to access quality health care as enshrined in the constitution. Access to health care in quality and outcomes are still largely dependent on an individual’s income and where they live, with rural areas being disproportionately affected.

The reality is that as a country we are still a long way from meeting the promise and right to access quality health care as enshrined in the constitution.

According to the District Health Barometer, the 10 most deprived districts in the country are all rural and, not coincidentally, fit neatly into the borders of the former homelands. Rural populations carry a double burden. Beyond the grave human resource shortages, they tend to also have higher out-of-pocket expenses such as transport costs to provincial hospitals when accessing public services.

For Grace the distances travelled to services and the costs involved are a barrier to her accessing the services she needs to stay healthy: *“Private practitioners are too expensive so it is not always clear what advancements have been made to better or improve my condition.”* She was unable to afford to travel 60km to the nearest facility to attend her monthly evaluation after her discharge from the public health facility.

Hendry from Tzaneen believes that transport to facilities needs to be available especially when suffering a relapse. *“I was referred to the hospital when I relapsed – it cost my family money for the taxi to take me to the hospital and to accompany me.”*

Where are all the healthcare workers?

Today 17% of the population who access private health care is served by about 70% of the country's medical practitioners, 60% of its specialists and half of its professional nurses. The latest South African Health Review paints a dismal picture of human resources for public mental health care services in South Africa. In the public sector there are only 2.6 occupational therapists, physiotherapists and psychologists for every 100 000 people in the country¹². The skills of specialist staff are even more concerning with only half as many psychiatrists in the public sector at approximately 1.2 psychiatrists for every 100 000 people¹³. There is a considerable contrast to this in the private sector where there are seven times more psychologists, five times more physiotherapists and three times more occupational therapists. These statistics are concerning and carry particular significance for the public health care sector, which serves the majority of the population, and face staff shortages that remain a significant challenge to delivering accessible healthcare to rural populations.

The risk of misdiagnosis due to lack of appropriately trained health care workers can have devastating consequences.

Ongeziwe from the Eastern Cape expresses his frustration at the lack of psychiatrists in his area: *"I need to see the psychiatrist to discuss my case as I would like to know if I am better now. I am just drinking medication again and again forever. I would like to know the name of my illness and what caused it."* Jill from the North West supports Ongeziwe's frustration: *"mentally ill people do not get the right diagnosis due to a lack of professionals."*

Data on psychiatric nurses and social workers is glaringly absent despite their being the cornerstone of mental health care services. Nurses continue to bear the brunt of service delivery for mental health services at PHC level. If task-shifting continues without commensurate extra human resources to accommodate the increased scope of work for nurses, then the strategy of delivering mental health services closest to communities will not succeed.

Jethro from KwaZulu-Natal explains how he values the service offered by a psychiatric nurse, but that this service is only available at the hospital. *"I prefer to collect my medication at the hospital because the professional psychiatric nurse advises us on how to recognise the early signs of relapse and to look after ourselves so that we are not taken as 'mad' people by the community members. This service is not done at the clinic which is nearer to me..."*

It is estimated that 40-45% of the population live in rural areas and about 12% of doctors and 19% of nurses work in rural areas. The dire shortage of human resources, lack of vital drugs and equipment and lack of accommodation are critical barriers to attracting and retaining staff in rural areas. All of these factors affect the motivation and ability of staff to effectively carry out their duties, resulting in the unmet needs of patients who ultimately carry the burden of a failing health system.

It's a crisis, and we need urgent action, not rhetoric!

Equity in access is a function of how and where the government invests in the health system. This does not necessarily mean privileging rural areas over urban areas or mental health over other health needs, but rather involves effective planning and investment in healthcare workers and health systems that can provide quality care.

The 'fatal' consequences due to the lack of human resources necessitate an urgent intervention. Equity in access and quality care should recognise that health care workers are the pillar of delivering mental health services.



Investing in rehabilitation is essential to addressing the gap in mental health care services in rural areas

Shannon Morgan
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Investing in rehabilitation is essential to addressing the gap in mental health care services in rural areas

One of the first objectives set forward in the National Mental Health Policy Framework is to strengthen district-based mental health care services. Within this objective, and the current developments towards the re-engineering of PHC, investing in rehabilitation is essential to addressing the gap in mental health care services in rural areas in South Africa¹⁴.

With the exception of a small number of specialist units, little or no rehabilitation is available to mental health care users in rural areas. Psychiatrists, psychologists, occupational therapists and social workers are often available only at tertiary or district hospitals which are far away and transport is costly for patients.

With the exception of a small number of specialist units, little or no rehabilitation is available to mental health care users in rural areas.

Challenges such as staff shortages and access to hospital transport prevent mental health care specialists from conducting outreach services to the communities where they are needed most. The result is that mental health care users may get medication but do not receive any psychological support or rehabilitation and are not routinely reviewed. The person consequently remains ill, is further isolated from their community and is at risk of becoming “the revolving door patient”.

In some cases people are only able to access the care they need when they become violent and are taken into custody by the police. Not only does this mean that the person suffers a prolonged period of mental illness before accessing care which can compound the severity of the illness, but it also results in high levels of family and community stress, violence and threats to safety, which particularly impacts on children. Traumatic events such as these are frightening and encourage negative perceptions about mental disorders which, in turn, contributes to the stigma and discrimination experienced by mental health care users in rural areas.

Ongeziwe expresses his struggle with the community’s perception of mental disorders: “My family knows (about my illness) but not my friends or anyone else. I think they will laugh at me if I tell them I take these pills.”

Rehabilitation services support mental health care users and their families in understanding their illness, reintegrating back into their community and resuming their life roles. As outlined in the National Mental Health Policy Framework: “mental health care users should have access to care near to the places where they live and work” and “a recovery model, with an emphasis on psychosocial rehabilitation, should underpin all community-based services¹⁴.”

Centralising rehabilitation services at hospitals may result in opportunities being missed in integrating psychosocial rehabilitation into existing community-based services and programmes. Community health workers play an essential role in connecting people with services, including home education and support, tracing and referral. Rehabilitation services at hospitals often work closely with community health workers as persons with a mental disability are vulnerable to becoming lost to service due to lack of follow-up. Mental health screening, basic counselling and referral should be included as part of community health workers training.

Community-based mental health care services are especially important in rural areas where there is a shortage and high turnover of health professionals.

Community-based mental health care services are especially important in rural areas where there is a shortage and high turnover of health professionals. In many instances nurses are the only health care workers at the primary level of care responsible for developing and implementing mental health care services.

“The clinic is always full so I do not receive any counselling from the clinic and I also wait for a long time to get medication. The clinic is not specialised and services both psychiatric and general patients.” – Hendry.

Creating access to rehabilitation by increasing the number of health care workers involved in mental health care at the PHC level needs to be strongly considered in the DoH’s human resources strategy for mental health. Due consideration should be given to creating training and posts for a cadre of mid-level rehabilitation workers that have the skills to intervene at community clinic level with support from rehabilitation departments at district hospitals.



“Not having access to medication is destructive”

Dr Meba Kanda

Rural Doctors Association of South Africa (RuDASA)

“Not having access to medication is destructive”

Rural areas are hardest hit by stock outs, as problems are exacerbated by logistical and human resource constraints...

According to the Stop Stock Outs Campaign, 10% of reported medication stock outs between January and July 2015 were psychiatric medications. Rural areas are hardest hit by stock outs, as problems are exacerbated by logistical and human resource constraints, such as large distances between facilities and understaffing¹⁵. This is not a new problem for the mental health care system as the WHO-AIMS report of 2007 already highlighted that there is a wide variation in the availability of psychotropic medication at PHC level¹⁶. The persistence of this problem is concerning and requires serious attention.

Njabulo from KwaZulu-Natal explains that in past experiences, *“the clinic did not have my medication and therefore there was a delay in receipt of the medication”*. He reported that it was incredibly concerning to him due to the importance that medication plays in the management of his health.

A survey to determine the views of mental health care users regarding prescribed psychiatric medications found that 99% of participants felt that medication was beneficial to their health and improved their quality of life¹⁷.

Dumisani from KwaZulu-Natal has also been affected by the unavailability of psychiatric medication at community-based level, forcing him to travel further from his home to access these. He reported: *“the clinic mobile point does not have mental health care user’s medication. Medication runs out and it is not yet time for the mobile clinic point services to arrive.”*

Stock outs of psychiatric medication at clinics leave patients in a precarious situation which can result in a deterioration in mental health functioning and, at times, relapse. This, in turn, can lead to a poorer quality of life and social isolation, and may also increase the chance of re-admission to inpatient facilities. Stock outs of psychiatric medication in rural settings is in direct contrast to the ambitions set out in the National Mental Health Policy Framework which promotes a model of recovery and stipulates that all psychiatric medication must be available at all levels of care.

Grace reflects on the impact that medication stock outs has had on her health and quality of life: *“It happens quite often that I cannot get the medication I need because the public hospital was out of stock. I needed to move to an available dosage that is lower and causes sleep disturbances.”*

Patrick has on one occasion been forced to purchase his own medication due to stock outs: *“I bought some medication from the nearest chemist until the government or the clinic that I go to was able to provide the proper service. Sometimes the medication is not available and I am referred to the hospital that is far and even there the medication is not available. Two months I did not receive Haloperidol as it was not available.”* Situations like this places significant financial strain on patients and has a negative impact on productivity and quality of life. Patrick explains: *“I feel weak and lack the energy to work and spend most of the day resting. When you don’t get medication it affects you a lot and it results in me not being able to do other things.”*

The availability of medication is one of the key components in delivering effective, quality rural mental health care services. For many people having access and availability to psychiatric medication is essential to their own recovery and management process. The lack of access to medication at rural clinics is more than a logistical or policy issue; it deeply impedes on people’s right to health and dignity. Sithembiso from KwaZulu-Natal expresses his frustration by saying that *“not having access to medication is destructive”*.

The availability of medication is one of the key components in delivering effective, quality rural mental health care services.

While the National Mental Health Policy Framework stipulates that all psychiatric medicines – as provided for on the standard treatment guidelines and essential drug list – must be available at all levels of care, it is clear that this is not yet happening. The Rural Mental Health Campaign would like to encourage provincial and district departments of health to place greater emphasis on ensuring that people's right to health and dignity are furthered through the availability and accessibility to all psychiatric medications in primary rural health care settings.



**“If health services are integrated it will
be better for poor people like us”**

Dr Meba Kanda

Rural Doctors Association of South Africa (RuDASA)

“If health services are integrated it will be better for poor people like us”

Neuropsychiatric disorders are ranked 3rd highest in their contribution to the national burden of disease after HIV and AIDS and other infectious diseases¹⁸. Although gains have been made in the provision of antiretrovirals at clinic level, mental health care services remain primarily hospital based. Research has shown that people living with HIV and AIDS have an increased chance of enduring a mental disorder over the course of their lifetime¹⁹.

Thembelihle who lives in a rural area in KwaZulu-Natal shares her challenges in accessing mental health care services: *“I was diagnosed with HIV in 1999 and then I was initiated on ARVs in 2004. As time went on I developed a mental health problem due to stress, and I started mental health treatment in 2010. To access ARVs is not a challenge – it is easily accessible. Doctors are always available when I am booked for an appointment. All services are in place. The challenge that I have is that mental health hospitals are very far from where I live. I need to take one or two public transport to reach the place.”*

Current predictions foresee depression as being the number one global burden of disease by 2030, surpassing heart disease and cancer²⁰. Depression has been associated with life-threatening illnesses such as HIV and AIDS and, in rural areas where there are fewer health care workers who may lack the skills and training to identify common mental disorders, the effects can be devastating¹⁹. A person living with HIV-AIDS is 36 times more likely to commit suicide than the general population¹⁹.

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A health care system which is biomedically orientated and hospital based is often far from rural communities. This current configuration of the mental health care system does not provide for the psychosocial and cultural needs of mental health care users living in rural areas. The lack of integration of mental health care services at PHC level results in multiple trips to the clinic or hospital. People living with a mental disorder and HIV and AIDS in rural settings find themselves and their family members frequently traveling as they have to attend separate clinics. As these different clinics do not share information there is a risk of duplication of investigations and interventions. This situation is costly for both the health care system and service users.

“To see psychologists takes long as they are fully booked, if I am lucky to get booked for an appointment, I don’t get a follow up date. The delay leads to me missing my doses sometimes and no follow up.” – Thembalihle.

The United Nations Rural Poverty Report (2011) indicates that poverty is still mostly concentrated in rural areas with an estimated 70% of people living on less than approximately R18 per day²¹. Poverty is a significant stressor to mental wellness and in rural areas is further exacerbated by the added costs of accessing health care.

“I depend only on a disability grant which is too little to take care of all my needs e.g. visiting two different hospitals on different dates and sometimes my grant will be used by my family for other necessary needs, like food, electricity and many more so I become bankrupt. At least if the health services are integrated it will be better for poor people like us.” – Thembalihle.

The mental health needs of people living with HIV and AIDS can no longer be ignored and HIV and AIDS programmes and services need to offer more than medical care and antiretrovirals.

Despite these difficulties Thembalihle remains optimistic: *“I would like to thank Department of Health because I am alive irrespective of the challenges I am facing on [a] daily basis.”*



**Statement by the Treatment Action Campaign
on Access to Rural Mental Health Care**
Anele Yawa
The Rural Mental Health TAC General Secretary

Statement by the Treatment Action Campaign

The Treatment Action Campaign (TAC) welcomes and supports the Rural Mental Health Campaign aimed at improving access to quality mental health care services for all who need it in South Africa.

We have for many years been concerned by the scarcity of quality mental health care services in the public sector and more specifically in rural areas. Mental health care services are difficult to access in rural areas as a result of travel distances and the costs and time involved. These factors combined with the paucity of mental health workers in rural districts, poses extra burdens on poor rural people.

While our focus is on HIV, we also recognise that there are mental health consequences for people living with HIV and AIDS. Sadly these are poorly identified and managed.

Learning that one is HIV positive can be very traumatic. Stigma is still rife in many of our communities and many of us struggle with both external and internal stigma.

Too often we suffer our mental health problems in silence and in shame.

One of the biggest problems facing the antiretroviral treatment programme today is the high rate of loss to follow-up. The three-year LTFU rate is estimated at 40%. The factors contributing to this high rate is not that well understood, but it is likely that depression and other mental health problems play a significant role. Some of us also experience psychological side effects from the antiretroviral drug efavirenz.

It is crucial that mental health care services are offered and integrated into antiretroviral treatment programmes across South Africa.

In short, we need much better mental health care services in the public sector firstly in the interests of the patients who need it and secondly to contribute to the success of our wider struggle against HIV.

It is crucial that mental health care services are offered and integrated into antiretroviral treatment programmes across South Africa.



Rural Mental Health Campaign Recommendations

The Rural Mental Health Campaign Report

Rural Mental Health Campaign Recommendations

The core recommendation for overall strategic orientation is to translate the National Mental Health Policy Framework and Strategic Plan (2013–2020) into provincial strategic and operational plans.

Systematic considerations must be made in the design of these provincial strategic and operational plans to ensure that rural actualities are adequately planned for. Provinces' plans must include targets, indicators, budgets and timelines that support the realisation of quality mental health care services for rural populations. Furthermore, as outlined by national policy, provinces' health departments must monitor and evaluate the implementation of the National Mental Health Policy Framework and ensure the provision of a sustainable budget for mental health services to develop the capacity of mental health departments and supporting structures.

Provinces' plans must include targets, indicators, budgets and timelines that support the realisation of quality mental health care services for rural populations.

The Rural Mental Health Campaign also proposes the following recommendations in support of the commitments made by the NDoH to improve the mental health care system.

1. The National Mental Health Policy Framework tasks provinces should accurately collect and use minimum datasets for mental health that are integrated into the general health information system at all levels. The Campaign recommends that the frequency of admissions to inpatient psychiatric facilities should be included as an indicator to monitor and evaluate the relapse rate of patients accessing inpatient psychiatric facilities. These indicators will help provide data to track improvements in the move towards community-based models of care.
2. The findings on the shortage of health care workers delivering mental health care services in rural areas are of major concern. The Campaign calls on provinces to formalise human resources strategies that are favourable to rural mental health care settings and are in line with the commitments of the National Mental Health Policy Framework.

3. Complementary to this human resources strategy, task-sharing and transdiagnostic community-based models should be explored in these settings in order to increase the reach of mental health care services and to ease the burden on specialist mental health care workers. Additionally, registered counsellors, counselling psychologists, mid-level rehabilitation workers, clinical associates and other already established registrations should be adequately trained in public mental health and seriously considered as a recruitment profile of the DoH. These profiles should be used to task-share services and essentially expand the coverage of mental health care services in rural settings. More focus needs to be placed on the absorption and recruitment of mental health care specialists in rural settings.
4. There is a need for mental health care services to extend beyond the physical parameters of rural clinics due to sparse rural populations and the limited number of mental health care professionals working in these rural areas. Transport must be prioritised for outreach services to further increase the reach of health professionals and their ability to offer community-based services and support. Furthermore patient transport vehicles are essential in creating accessible services and play a vital role in the promotion of mental health and prevention of relapse in rural areas. The availability of transport from rural clinics to Community Health Centres and district hospitals will greatly increase access to mental healthcare services.
5. Those working on the Campaign are greatly concerned by several testimonies of stock outs of psychiatric medications. More attention by all mental health stakeholders needs to be placed on ensuring that all psychiatric medicines, as provided on the standard treatment guidelines and essential drugs list, are available to people living in rural communities.
6. Stigma and discrimination remain significant barriers that continue to prevent mental health care users from accessing mental health care services. The National Mental Health Policy Framework speaks of mental health care user participation in implementing the policy, but from the testimonies it is clear that this is not happening. For mental health care users to become effective participants in the implementation of the National Mental Health Policy Framework and to fully enjoy all their constitutional rights, active measures must be taken to empower mental health care users. Consultation and collaboration should extend to mental health societies and mental health care users on the most effective and efficient ways to reach communities in rural areas. Awareness must not only be targeted at the community at large, but also among all health care workers and must include training on the rights of persons with mental disability. Furthermore government must support advocacy initiatives of community-

based organisations. It is integral that a national public education programme for mental health extends to rural settings and is integrated within district services.

7. Mental health services must be integrated into HIV/AIDS programmes and services at PHC and district levels (WHO, 2008). Primary and district level staff who manage patients living with HIV must routinely assess and treat for mental, neurological and substance-use disorders. Furthermore, community health care workers should be adequately trained to screen for mental health-related disorders, provide basic counselling and referral.



References

References

¹ Herman AA, Stein DJ, Seedat S, Heeringa SG, Moomal H, Williams DR. The South African Stress and Health (SASH) study: 12-month and lifetime prevalence of common mental disorders. *South Afr Med J Suid-Afr Tydskr Vir Geneesk.* 2009 May; 99(5 Pt 2): 339–44.

² WHO, Global burden of mental disorders and the need for a comprehensive, coordinated response from health and social sectors at the country level, December 2011 (WHO, Executive Board 130th session, 01 December 2011).

³ Funk M. Global burden of mental disorders and the need for a comprehensive, coordinated response from health and social sectors at the country level.

⁴ Williams DR, Herman A, Kessler RC, Sonnega J, Seedat S, Stein DJ, et al. The South Africa Stress and Health Study: rationale and design. *Metab Brain Dis.* 2004 Jun; 19(1-2): 135–47.

⁵ Herman AA, Stein DJ, Seedat S, Heeringa SG, Moomal H, Williams DR. The South African Stress and Health (SASH) study: 12-month and lifetime prevalence of common mental disorders. *South Afr Med J Suid-Afr Tydskr Vir Geneesk.* 2009 May; 99(5 Pt 2): 339–44.

⁶ Bloom DE, Cafiero E, Jané-Llopis E, Abrahams-Gessel S, Bloom LR, Fathima S, et al. The global economic burden of noncommunicable diseases. *Program on the Global Demography of Aging*; 2012.

⁷ Lund C, Myer L, Stein DJ, Williams DR, Flisher AJ. Mental illness and lost income among adult South Africans. *Soc Psychiatry Psychiatr Epidemiol.* 2013; 48(5): 845–51.

⁸ World Health Organization. Dept. of Mental Health, Substance Abuse. *Mental health atlas 2005.* World Health Organization; 2005.

⁹ Bateman C. The price of depression: under-budgeting for mental health is costing SA billions. *Noseweek.* 2014 Dec 1.

¹⁰ National Mental Health Policy Framework and Strategic Plan 2013–2020. South African Department of Health; 2013.

¹¹ Eagar D, Versteeg-Mojanaga M, Cooke R. Discussion Document: Defining rurality within the context of health policy, planning, resourcing and service delivery. *Rural Health Advocacy Project*; 2014.

¹² SAHR 2013/2014

¹³ HPCSA 2015 verbal communication

¹⁴ National Mental Health Policy Framework and Strategic Plan 2013-2020. South African Department of Health; 2013, (p. 20).

¹⁵ http://stockouts.org/uploads/3/3/1/1/3311088/stockouts_2014_final_online.pdf

¹⁶ http://www.who.int/mental_health/evidence/south_africa_who_aims_report.pdf

¹⁷ Sunkel, C. 2013, Empowerment and Partnership in Mental Health-Discovering their voice, Lambert Academic Publishing, p. 59–64.

¹⁸ Ref Crick Lund, Dan J Stein, Joanne Corrigall, Debbie Bradshaw, Michelle Schneider, Alan J Flisher June 2008, Vol. 98, No. 6 SAMJ Editorial Mental health is integral to public health: A call to scale up evidence-based services and develop mental health research

¹⁹ L Schlebusch MA(Clin Psych), MMedSc(Psychiat), PhD, C Psychol(UK), FRIPH(UK) (2005) Depression and suicidal behaviour, South African Family Practice, 47:5, 61–63, DOI: 10.1080/20786204.2005.10873234

²⁰ WHO, Global burden of mental disorders and the need for a comprehensive, coordinated response from health and social sectors at the country level, December 2011

²¹ Rural Poverty Report 2011, IFAD (<http://www.ifad.org/rpr2011/index.htm>)