24 August 2017

South African Human Rights Commission

National Hearing on the status of Mental Health in South Africa
Submission by the Rural Mental Health Campaign

Introduction to the Submission

Why does a Rural Mental Health Campaign exist?

The Rural Mental Health Campaign (RMHC) was started in 2014 by a group of organisations who are advocates for rural health as well as mental health care services in South Africa. These organisations remain concerned about the lack of access to mental health services and the lack of progress made in the implementation of the National Mental Health Policy Framework and Strategic Plan (NMHPF) which was released in 2013. The RMHC is also advocating for policy to be "rural proofed" so that the context and specific needs of rural populations be considered in strategic and operational planning for mental health care service delivery. To highlight the dire circumstances in which many rural people with mental health issues live we present a case from the Eastern Cape (below).

Case Study: Eastern Cape
(Case study based on a real family. Names have been changed to protect their identity)*

Sidumo* is a 65 year old man who lives with his brother, his two sons, his wife and a caregiver in a deeply rural village in South Africa. You cannot drive to his home as there are no roads. The only way to get to his home is on foot over steep hills. Sidumo was diagnosed with Schizophrenia in 2013. He was hearing people calling his name and his ears would hurt so much it would make him cry out with pain. He was started on an injectable antipsychotic Modecate.

Sidumo's younger brother, Siyabonga*, is 36 years old and also has Schizophrenia. He also started becoming ill around the same time as his brother but he became very violent. He broke the windows of the house and the family were very afraid of him. He was started on Clopixol and has been stable on his medication since then. Even though he is stable he struggles to interact with others and he is not able to find a job to help support the family.

Sidumo's oldest son Anga* is 18 years old and started becoming ill last year. He was seeing people who weren't there and acting strangely. He was taken to the nearest district hospital and he was seen by doctors and occupational therapists. The assessment results differed for Anga. An intellectual disability with psychosis or a mental disorder manifesting for this first time. He was also referred to the Tertiary hospital's mental health care unit but he missed that date. This was due to financial problems but importantly also the strain that the main caregiver in the home is taking as she tries to manage all the health needs of this home. It's a year later and his diagnosis still needs to be made. Without a diagnosis and an ID (identity document) he won't be able to apply for a Disability Grant. This means the family's out of pocket expenditure on his health needs will continue to affect the whole family's livelihood and health.

This becomes evident when assessing the younger son Sive* who is 13 years old. He may also have an intellectual disability, has dropped out of school and struggles with basic concepts. He needs a formal assessment but the family cannot cope with the expenses of taking him to services too. He will need to wait till his older brother is more stable. This could still take a while longer as Home affairs is located 50km away and again the family needs to spend money and time getting there.

There is one relative who has become a caregiver for the family, Nomonde. She came to live with the family many years ago as Sidumo's wife also has an intellectual disability and she was struggling to look after her husband's health care needs. Nomonde has in the past even had a marriage proposal but she turned it down because she would have had to leave the family and she couldn't bring herself to do this.

Sidumo's medication has recently been out of stock at the clinic and the hospital. He has been changed to another medication but it's not working. The pain is back in his ears and at night he doesn't sleep but he stands outside and cries so loudly that the neighbours have started phoning to complain. He's quite aware that his medication is not working and he just wishes the pain would go away and that he can sleep again.

What have we done?

Our 2015 report included the testimonies of mental health care users from rural areas who shared the challenges they face in accessing care. The findings showed that rural mental health care services are still largely inadequate, due to the inaccessibility of existing services, budgetary constraints, psychiatric medication shortages, insufficient human resource capacity and a lack of integrated care, as well as stigma and discrimination.

The RMHC may not have been successful, or even have reached the Ministerial advisory committee, if it didn't appreciate the important role of mental health care users in their own self advocacy and that no interventions should be planned without their voices:

"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."

"People see mentally ill people as being mad and should be locked away in an institution"

"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."

"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."

What, in your view, are key challenges confronting the mental health care sector broadly?

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 treatment (Herman et al, 2009). 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 all (WHO, 2011). As with the case study below one can see why people living in rural areas may have limited or no access to mental health care treatment.

Rural areas account for almost half the country's populations yet remain at the margin and periphery of political, economic and social centres of power. This situation has made rural populations hard to reach. Relative progress has been made on the reengineering of Primary Health Care (PHC) but rural mental health care services are still largely inadequate. Often, unseen and unheard, rural populations are left victim to many forms of suffering for years.

The NMHPF, which is an important achievement for mental health, does refer to this significant population but implementation in rural areas remains negligible. In addition, this important document does not provide details of how the inequality experienced by rural populations should be addressed. The neglect of the mental health of rural populations often results in a burden on the limited resources situated in urban centres as people from rural areas come to seek treatment in urban settings. The poorest, however, remain excluded as they cannot meet the expenses of travel.

Poverty, violence and displacement are the major social determinants of health, including mental health. The interaction between these social determinants and mental health is complex and multidirectional. Rural populations remain victims of poverty with higher unemployment rates as compared to urban populations. One is tempted to suggest that there

is a triple burden faced by rural populations based on being rural, living in poverty and a having mental health disorder.

It is for families such as Sidumo's that our committee volunteer our time and resources.

In your view, what key priority areas require the allocation of more resources in order to adequately accommodate the varied needs of MHCUs?

Our 2015 report found the following challenges existed in the delivery of mental health care services in rural South Africa.

- Inaccessible services, mostly sited in urban tertiary centres;
- Grossly inadequate budget allocations for mental health by provinces;
- Frequent drug stock-outs, leading to high relapse rates;
- Lack of human resources for mental health
- Lack of psychosocial rehabilitation at District and community level, resulting in poor recovery and "revolving door" care
- Prevailing stigma and discrimination within communities and within the health service

Challenges for rural mental health learnt from the Life Esidimeni Tragedy

Deinstitutionalisation and bringing mental health services closer to where people live is an priority of the NMHPF, but we have all witnessed the devastating effects for patients and their families when this is done without adequate planning and coordination. Sadly the events in Gauteng are only the tip of the iceberg: all over the country, and especially in rural areas, mental health care users have little or no access to the services they need, resulting in the same devastating effects on individuals and families.

The Life Esidimeni tragedy not an aberration: it simply places in the spotlight what is happening everywhere.

Deinstitutionalisation is key to rights-based mental health care and should not be abandoned. Instead there should be clear guidelines developed to ensure the appropriate placement of people with mental health care needs – some of whom will be able to live as part of their communities, and some of whom will continue to require residential care. The capacity of both community-based services and residential facilities must be strengthened, including those run by NGOs, and clear supervision policies implemented as envisaged in the strategy. Whilst there are community care centres in rural areas these are often started by concerned family members or community members, they indicate need but will not comply with the registration requirements for care centres.

While fiscal consolidation and shrinking budgets are likely to stay with us for some time, policy makers need to consider the impact of austerity measures on the most vulnerable in our society, including people living with mental disorders.

As the RMHC, we strongly support the Health Ombudsman's recommendation that the "National Minister of Health should request the South African Human Rights Commission (SAHRC) to undertake a systematic and systemic review of human rights compliance and possible violations nationally related to mental health" and we call for this to take place through engagement with mental health care users and their families. According to Jethro, a mental health care user from Kwazulu-Natal, "People tend to disregard a mad person's opinions on issues of discussions" (RMHC report 2015). We cannot go forward without acknowledging mental health care users as key partners in upscaling mental health care services and this can be realised by actively supporting and resourcing patient advocacy groups in both rural and urban areas.

It is time to start listening and working together so that decisions are made collaboratively and don't result in gross human rights violations. NGOs, who provide the majority of community-based services for mental health care users, do so with minimal support from government. The Gauteng tragedy has unfortunately placed such NGOs in a bad light, particularly as some of those involved were found to be operating with invalid licences. What this tragedy has proved however (and what we already know) is that there needs to be a partnership between government and NGOs, and NGOs must be acknowledged as key role-players in achieving the goals and objectives of the NMHPF. Without this, the Mental Health Strategy will remain nothing more than intentions on paper

What are your proposed recommendations to address these challenges?

Our goal would be to see good mental health care being provided as part of PHC in every rural community.

The testimonies of mental health care users demonstrate how existing PHC services fail to address the complex needs of someone with mental illness, with serious consequences for rural communities.

The RMHC therefore recommends strengthening and developing PHC Mental Health services in rural areas, including the following:

- Ensuring access to medication at clinics and mobile clinics in communities.
- Adequate emergency medical services that are accessible to mental health care users.
- Psychosocial rehabilitation at community level that supports mental health care users to participate in community life through inclusion in life, learning and social roles.

To realise the latter, Rehabilitation cannot simply be tacked on to existing job descriptions, but require cadres with specialist skills: mid-level rehabilitation workers, occupational therapists, social workers and psychologists, among others.

Please see our attached 2015 report for more information and testimonies of mental healthcare users.

Conclusion

As the RMHC we urge the South African Human Rights Commission to use this opportunity to investigate the needs of all mental healthcare users in our country, rural as well as urban. Unless rural healthcare services are strengthened alongside their urban counterparts, human rights abuses towards people living with mental illness will continue, unseen and unchecked, across South Africa.

We thank you for this opportunity to share our experience and recommendations.

Submission made by the RMHC Committee members

- Shannnon Morgan, Rural Rehab South Africa (RuReSA), Campaign Chairperson
- Mafoko Phomane, Rural Health Advocacy Project (RHAP), Campaign Secretary
- Meba Kanda, Rural Doctors Association (RuDASA)
- Kate Sherry, Rural Rehab South Africa (RuReSA)
- Richard Vergunst, Psychology Department, University of Stellenbosch
- Ingrid Daniels, Director of Cape Mental Health
- Charlene Sunkel, Programme Manager: Advocacy & Development, SA Federation for Mental Health
- Maggie Marx, Programme for Improving Mental Health Care (PRIME), Communications Officer

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- 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).
- The Rural Mental Health Campaign Report, 2015, http://www.ruresa.com/rural-mental-health-campaign.html