

SOUTH AFRICAN FEDERATION FOR MENTAL HEALTH (SAFMH)

The SA Federation for Mental Health is a registered national, not for profit, non-governmental organisation (000-238 NPO), constituted by 17 mental health societies and 107 member organisations, all actively involved in the field of intellectual and psychosocial disability and mental wellbeing. The organisation was established in 1920 with the aim to coordinate, monitor and promote services for persons with intellectual and psychosocial disability, as well as promoting good mental health and wellbeing amongst the South African public. (www.safmh.org)

SOUTH AFRICAN MENTAL HEALTH ADVOCACY MOVEMENT (SAMHAM)

The South African Mental Health Advocacy Movement (SAMHAM) was established by SAFMH in 2007 in recognition of the importance of giving persons with psychosocial and intellectual disabilities a voice, and further recognising that they are ultimately the experts in mental health and should thus always be key partners among all stakeholders within the mental health sector. Outside of the mental health field and within communities, persons with psychosocial and intellectual disabilities must be empowered to participate at all levels of their lives. Prevalence rates of stigma attached to these disabilities are very high (not just in SA, but worldwide), which creates barriers in accessing and enjoying all rights enshrined in the South African Constitution's Bill of Rights and other relevant policies and legislation such as the UN Convention on the Rights of Persons with Disabilities. Persons affected by these "invisible" disabilities however play a crucial role in breaking down these barriers through being empowered and actively engaging with the public and private sectors, and expressing their concerns, needs, challenges and working together to overcome these. Because of their personal experiences, these individuals are also a key source of awareness on mental health, with direct access to and in-depth knowledge about specific communities across South Africa.

People with psychosocial and intellectual disabilities themselves are however yet to effectively communicate and raise awareness about their needs and to self-advocate on all public platforms for their rights to be implemented and their challenges to be addressed. The lack of a strong national self-advocacy movement results in continued social isolation and marginalisation of these individuals. In this way, human rights violations continue unmonitored and ignored, which result in unequal and limited access to resources and protection. These conditions impact directly on the material and lived reality of persons with psychosocial and intellectual disabilities.

The Dept of Health's National Mental Health Policy Framework and Strategic Action Plan for 2013-2020 emphasises (in point 7.5 on Advocacy) that there is a commitment from the Dept of Health to (4) "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 (5) "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". It is critical that this be continuously prioritised and that persons with

psychosocial and intellectual disabilities continue to be empowered and are able to fully participate within the ambit of these activities and to successfully achieve these goals.

Thus far, advocacy groups have been established in some provinces, functioning at different levels. However, they very often still lack sufficient capacity to be strong, united and representative voices for persons with psychosocial and intellectual disabilities at a national level. This is where SAMHAM is of vital importance, as it has an extremely important role to play in the strengthening of existing advocacy groups, supporting the establishment of advocacy groups in parts of the country where such groups are still lacking, whilst at the same time also identifying individuals with leadership potential and developing them into leaders for the mental health movement around which ongoing advocacy and awareness activities can be built.

SAFMH has developed an intensive 4-year strategy for the period 2015/2016 - 2018/2019, to support the establishment of mental health care user advocacy groups in all 9 provinces of South Africa, with the aim of creating a well-coordinated, effective national advocacy movement through which mental health care users can be empowered and which can be developed into an effective contact-based awareness vehicle:

- Year 1 (2015-2016): Mpumalanga and Northern Cape (completed)
- Year 2 (2016-2017): Free State and Limpopo
- Year 3 (2017-2018): North West and Kwazulu Natal
- Year 4 (2018-2019): Gauteng, Western Cape and Eastern Cape.

The provinces have been selected based on the scale of work needed to help develop effective advocacy work in the provinces, taking into consideration the sizes of the provinces and what has already been done (or not). Provinces with the highest need are prioritised first, leading to provinces with more established advocacy groups, which might just be in need of some degree of coordination, or assessing areas not currently covered by the Mental Health Societies.



At the centre of the awareness agenda is the need to address stigma and discrimination, and SAMHAM provides an excellent vehicle for doing so. In the report on the 5th International Stigma Conference, which took place in Canada in June 2012, a number of key messages emerged, which highlighted many of the issues within the international study of stigma and discrimination that needed to be taken forward, amongst others stating that it is important to:

- Include persons with mental illness in the designing of services
- Focus on contact-based education (between persons with mental illness and persons with stigmatising attitudes)
- Tailor programmes for specific audiences, considering specific cultural and contextual issues

Against this backdrop, SAMHAM provides SAFMH (and South Africa) with the perfect structure to build a responsive mental health advocacy and awareness structure.

As part of the aforementioned strategy, two provinces will be targeted each year, starting with the ones that require more extensive work and concluding with provinces that are already involved in advocacy work and already have functioning advocacy groups in place. The reality is that South Africa has vast distances that need covering, and implementing the SAMHAM strategy over a 4-year period allows for a thorough developmental process.

SAMHAM Advocacy Development Methodology

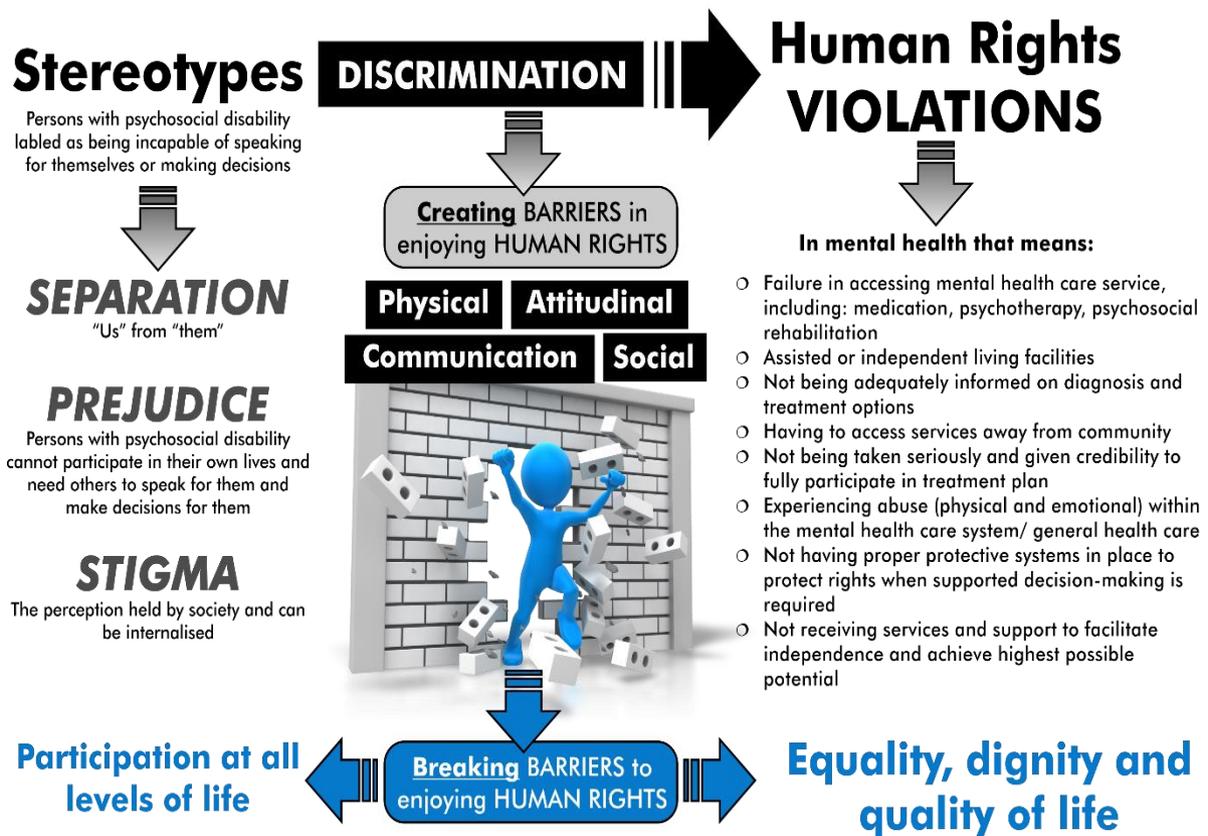


To date, SAMHAM has completed its first year of the strategic plan, which focused on Mpumalanga and Northern Cape, and was funded by National Department of Health (excluding the site visit to Lyndenburg in Mpumalanga which was funded in-house). This has provided SAFMH with further direction and the opportunity for the refinement of the model used, to adapt to the specific / unique settings within the various provinces. It has been a learning curve and valuable data was retrieved during this first year of the plan.

Lastly, it is also foreseen that SAMHAM will form a key component of SAFMH’s ongoing efforts to improve the reporting of human rights violations in South Africa, as it will provide an infrastructure through which mental health care users and their families can report and escalate human rights violations from community-based settings across SA.

SOCIAL MODEL OF DISABILITY

Psychosocial disability is not only based on a medical model - it is not just the symptoms experienced that causes disability, BUT is additionally a social model where stigma and discrimination leads to human rights violations that in turn result in disability. Disability caused via the social model can be overcome, provided the barriers created are removed. The UNCRPD focuses on the social model to eliminate disability.



In the illustration above it is explained how stigma and discrimination develops and how it leads to human rights violations.

SAMHAM takes specific focus on the UNCRPD which is structured on a social model. The UNCRPD features strongly within the plans and activities of SAMHAM and as an advocacy body representing its members.

The mental health sector specifically experience extremely high levels of stigma and related discrimination. Being an 'invisible' disability it is often not recognised under the broader disability umbrella, impacting on enjoying equality, dignity and quality of life of all persons with a diagnosis of mental disability.

SAMHAM recruits “leaders” from the various provinces to continue the work of SAMHAM in communities whilst being supported remotely by the programme manager at SAFMH National Office. Their role and recruitment criteria is as follows:

SAMHAM – Role of a leader

The definition of a SAMHAM leader is:

- A person with a psychosocial or intellectual disability who have grown as a human being through their experiences living with a disability
- Someone who feels passionate about adding value to the lives of others who struggle with their own disability
- Someone who is determined and motivated to improve the lives of persons with disabilities
- Someone who uses initiative and innovation to overcome challenges and address needs of communities
- Someone who is eager to gain as much information as possible, to empower themselves and transfer that information to others
- Someone who develops their own talents and skills and apply it to what they do every day

What you DON'T need to become a SAMHAM leader:

- You don't need a matric or higher education or whatever qualification – as long as you can speak, read and write in English so that you are able to communicate effectively with the programme manager and be able to participate in meetings, forums and conference, and/or with the media
- You don't need to know everything about psychosocial and intellectual disabilities or everything about human rights – that you will learn over time and at a pace that you are comfortable with, and with full support from the programme manager
- You don't need an office or a car – as long as you have access to a cell phone and email for the programme manager to be able to keep in contact with you and consider your community to be your 'office' because that is where and with whom you will work together with
- You don't need to have instant confidence to speak like a pro in front of an audience – only when you feel that it is what you want to do, and at the same time remember that gaining confidence to speak at public platforms comes with time and experience

The duties of a SAMHAM leader:

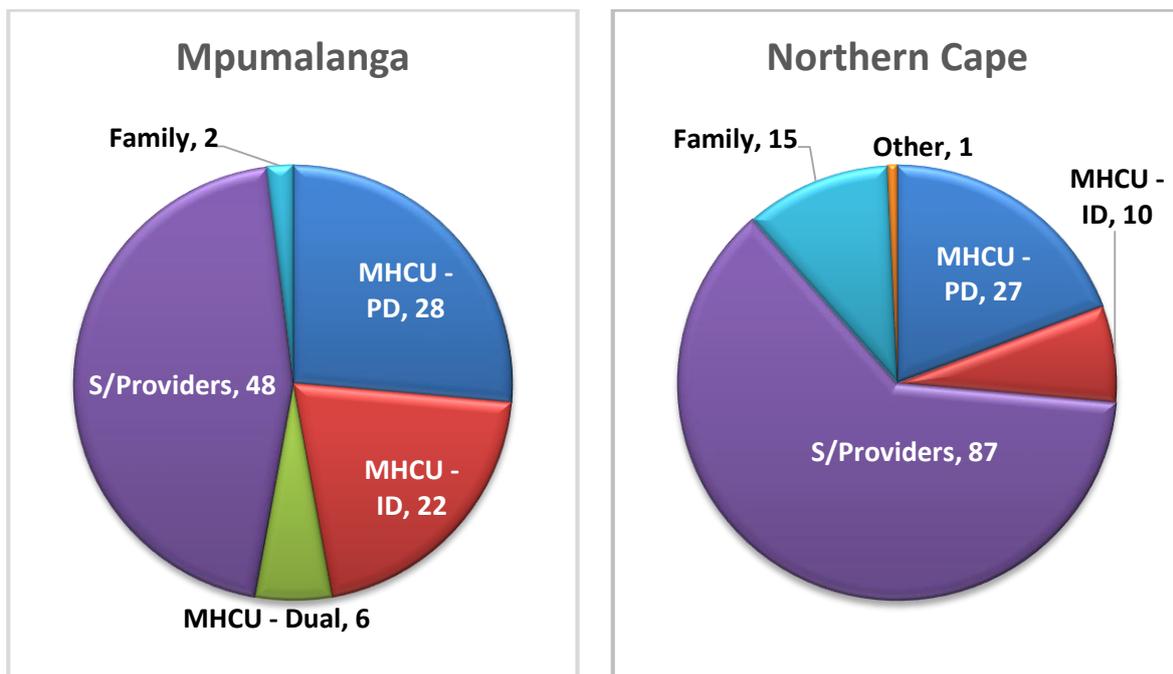
- Build a relationship with your community, especially those with psychosocial and intellectual disabilities – let them know that you are a SAMHAM leader and what SAMHAM is all about
- Create partnerships with stakeholders and service providers including clinic nursing staff and other NGOs in the disability/health field
- Constantly engage with persons psychosocial and intellectual disabilities, listen to what they are saying – what their challenges and needs are, what their views and opinions are around topics related to mental health and human rights – this information you escalate to the programme manager
- Attend local events hosted by Government and other stakeholders – and take on opportunities to be a speaker when requested (to share your story or talk on SAMHAM and the work you do in your community)
- If there is no support of advocacy group in your community, start one – let it be a space where persons psychosocial and intellectual disabilities can voice their concerns, ideas and hopes for the future, belong to the group and not be isolated, and where they can obtain information to empower themselves
- Cases related to human rights violations, escalate it to the programme manager unless you are able to refer the case to relevant channels to access justice

Site visits and Empowerment Sessions

As part of the 4-year strategic plan, site visits are conducted in the respective provinces. The various locations visited are assessed to get a better picture as to what resources are available or lacking. Empowerment Sessions are conducted and from discussion derived during the session, gives a broader perspective on the situation related to mental health.

Comparative findings of the experiences of mental health care users in MPUMALANGA and NORTHERN CAPE that were visited in 2015 indicates various challenges and needs.

Total participants per province, who attended the Empowerment Sessions

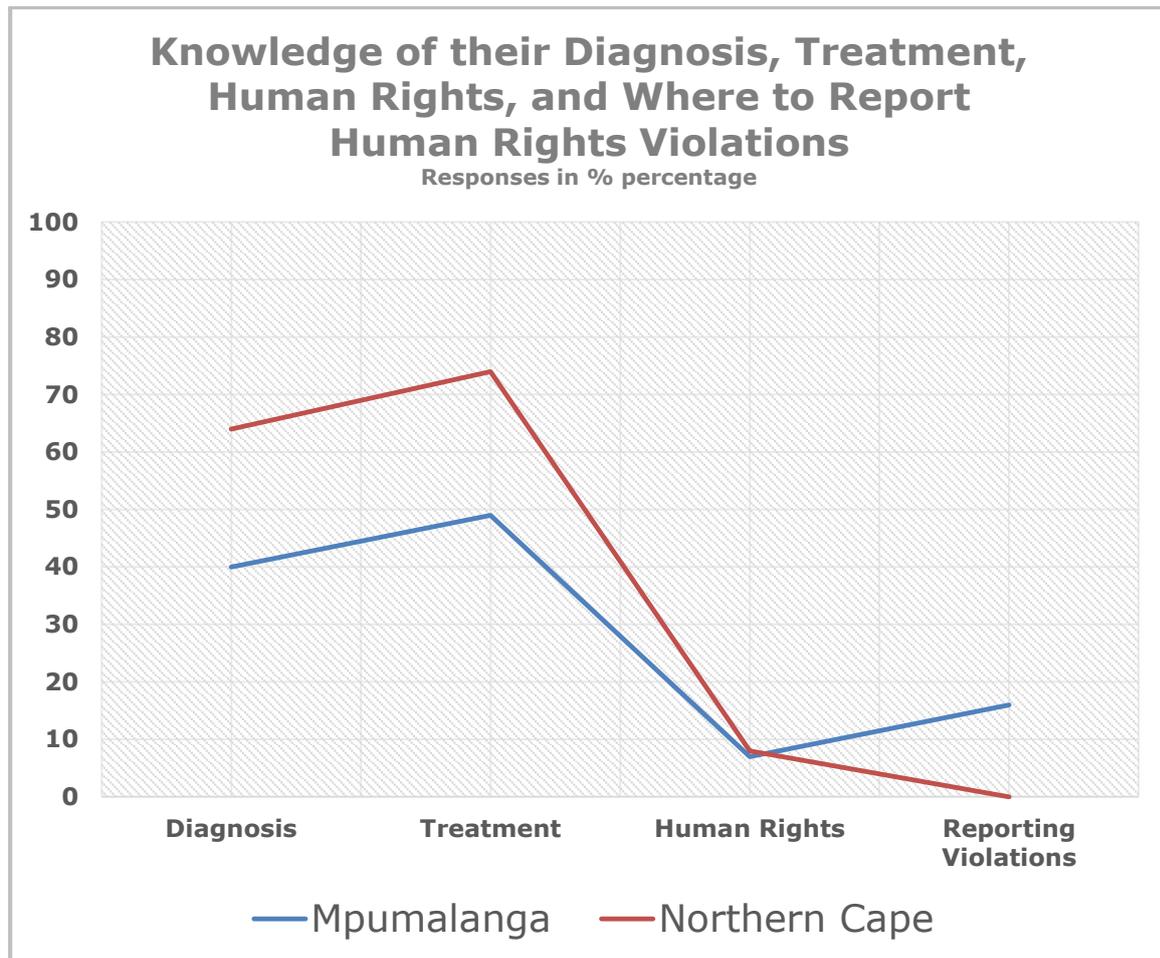


*MHCU - PD = Mental Health Care User with Psychosocial Disability
MHCU - ID = Mental Health Care User with Intellectual Disability
MHCU - Dual = Mental Health Care User with Dual Diagnosis (PD + ID)
Family = Family/relative of Mental Health Care User
S/Providers = Service Providers working with Mental Health
Other = include Journalists and non-health care workers not elsewhere specified*

Basic education (matric) – in Mpumalanga province only 1 service user completed matric and accessed higher education (but did not complete the degree) and in the Northern Cape 1 completed matric and has a higher education degree. The main reason for most who failed to complete high school was due to the onset of mental disorder occurring during high school years where others mainly due to intellectual disability did not access mainstream schooling. The lack of formal education was clearly a huge barrier in accessing employment, despite the ability of several of the service users to be employed in various levels of employment.

Work and employment – of all the service users who participated in the sessions, in Mpumalanga only 1 were employed in the open labour market and 8 worked at a protective workshop and in the Northern Cape province only 1 were employed in the open labour market whilst 8 worked at a protective workshop.

Knowledge assessment of mental health care users, prior to the Empowerment Session



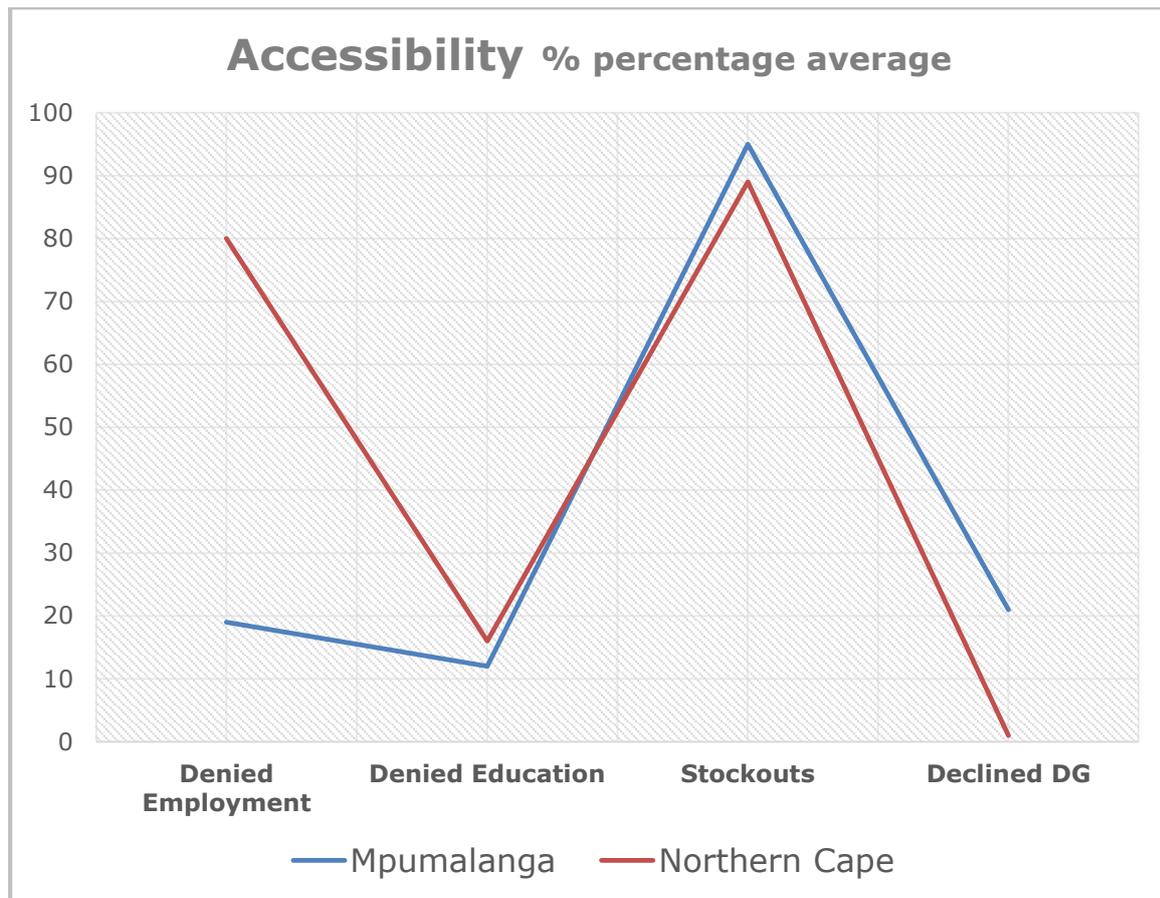
Diagnosis – mainly those with mental disorder knew their diagnosis whereas majority of those with intellectual disability were not aware of their diagnosis. But the ones who knew, only knew the name of their diagnosis and not what it is all about or what the specific symptoms are.

Treatment – the majority of those who responded that they knew what treatment they were prescribed, did not know the names of the medication or what exactly it is prescribed for, they only know how the tablets looked like and when to take which tablet.

Human Rights – shockingly very few knew any of their rights and those who responded that they had knowledge of their rights, their knowledge were somewhat limited and insufficient.

Reporting of Violations – again it was shocking to see how little actually knew what to do about or where to report a human rights violation.

Accessibility – Services and Life Opportunities



Denied Employment – service users’ experience where they were specifically denied employment due to their mental disability.

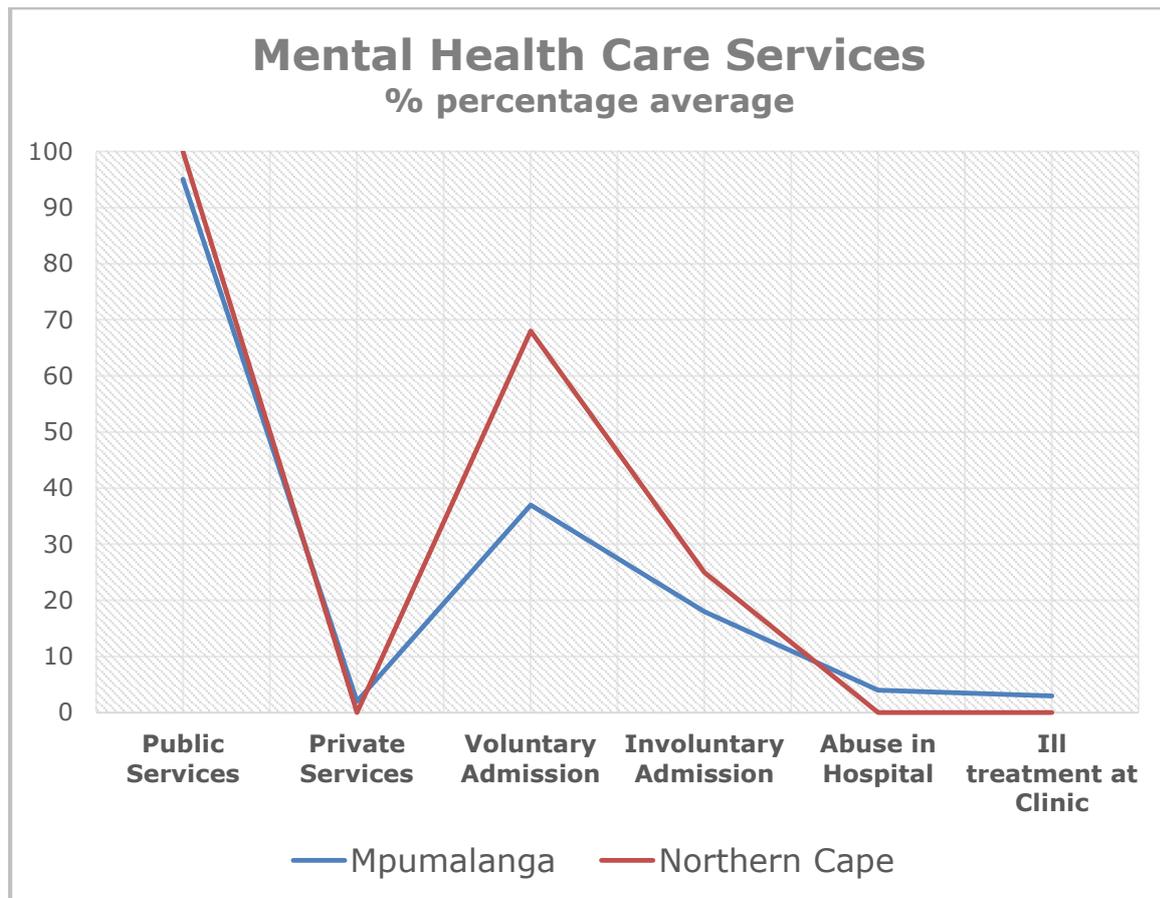
Denied Education - service users’ experience where they were specifically denied access to education due to their mental disability. Social workers reported that parents are often the ones denying access to education due to the belief that the service user is unable to be educated – this related to stigma and ignorance.

Stockouts – service users’ experience of stockouts of psychiatric medication at local clinics and hospitals. Stockouts is also not only restricted to medication not being available but also mental health professionals not being available.

Declined DG – mostly service users with psychosocial disability experienced unfair declines of disability grants whilst they do fit the criteria and despite motivation from the treating psychiatrist. This does seem to be a problem that occurs widely, from reports received, mostly from the Gauteng province, it appears that it is specific to certain SASSA offices. It does appear that it is not such a major problem in both Mpumalanga and the Northern Cape.

Accessing employment, education, adequate health care service and social security are all basic human rights.

Mental Health Care Services



Public Services – participants who accessed public mental health care services.

Private Services – participants who accessed private mental health care services.

Voluntary Admission – participants who had been voluntarily admitted to hospital for their mental disability.

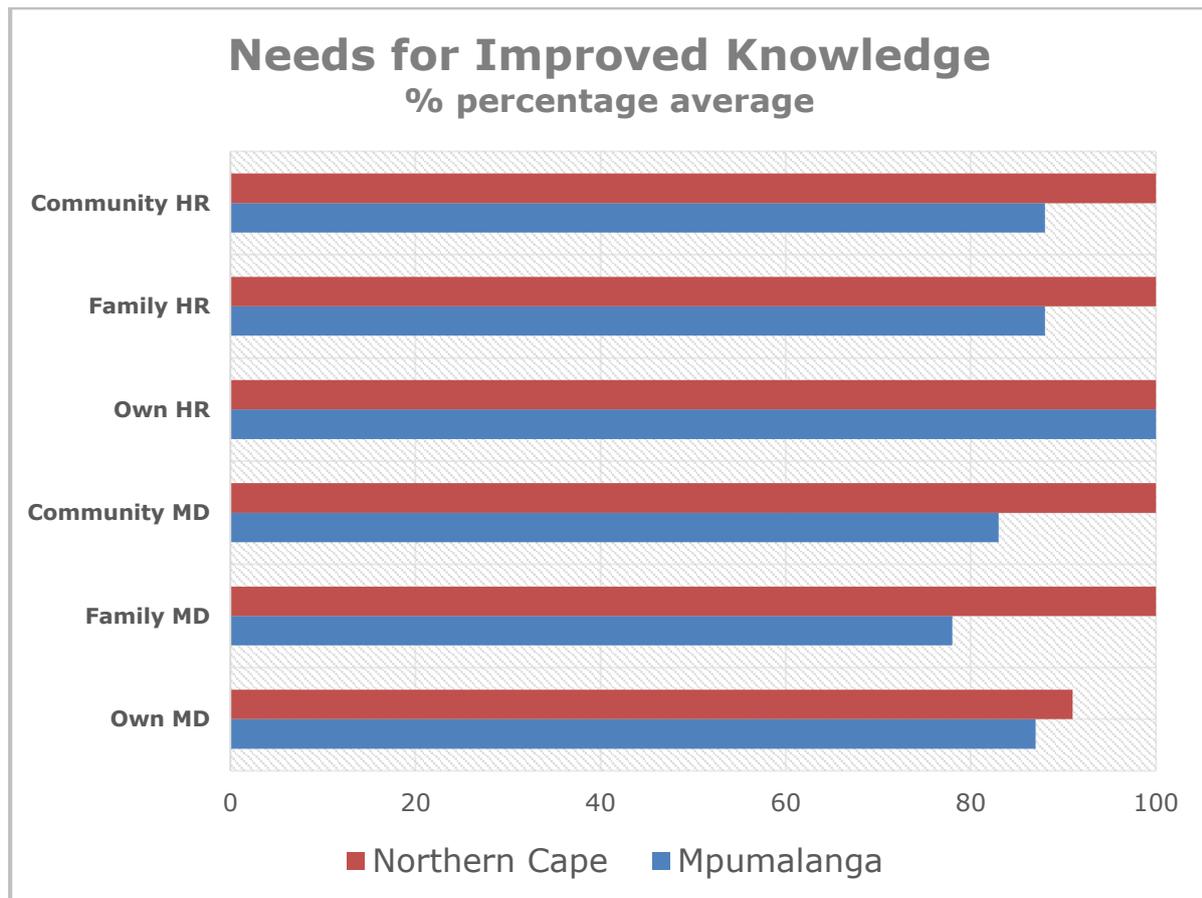
Involuntary Admission – participants who had been involuntarily admitted to hospital for their mental disability.

Abuse in Hospital – participants who had been hospitalised and who experienced any form of abuse whilst in hospital.

Ill treatment at Clinic – participants who accessed public mental health care services and who experienced ill treatment from clinic staff.

*It was inspiring to see how dedicated the nursing staff at clinics were towards their mental health care users. Many of them sadly reported that the general health care nurses often treat service users with disrespect when they access services for general health problems, and one nurse even shared that the general health nurses at the local hospital refuse to work with her mental health care users and would phone her to deal with them.

Needs Identified by Service Users – Improved Knowledge



Community HR – need for improved knowledge on Human Rights of the general community.

Family HR – need for improved knowledge on Human Rights of family members.

Own HR – need to improve own knowledge on Human Rights.

Community MD – need for improved knowledge on Mental Disability of the general community.

Family MD – need for improved knowledge on Mental Disability of family members.

Own MD – need to improve own knowledge on Mental Disability.

*The lower need for improved knowledge in Mpumalanga in comparison to the Northern Cape, can be somewhat contributed to the Mental Health Societies that exist in that province who play a vital role in awareness raising within communities around the understanding of mental disability specifically, whereas the Northern Cape has no organisations specific to mental health, except for the Kimberley area. The role of psychiatric nurses also had an impact on the level of service user knowledge on mental disability, where they inform service users, but in many cases the nurses (not always psychiatric) don't have the time to allocate for discussions with service users around their condition.

Needs for Services

Identifying one key component to service delivery that is required in the respective provinces, and that will address many of the challenges and needs raised in the discussions within the various communities – is:

MPUMALANGA

Mpumalanga is in dire need for psychosocial rehabilitation/ assisted living facilities for persons with both psychosocial and intellectual disabilities.

Although many service users live with family, it is not necessarily ideal for their recovery or for the protection of their human rights. Other service users have no family or the family wants nothing to do with them. Common incidents that had been reported was service users being discharged from hospital or being kicked out of the family home with nowhere to go and end up having to survive on the streets.

The benefits of providing psychosocial rehabilitation/ assisted living services to mental health care users in this province, include:

- Preventing families from exploiting and abusing them, in most cases for their disability grants
- Living with others they can relate to and where they can support each other instead of living in isolation
- Being provided with adequate meals and proper living conditions
- Participating in activities that can stimulate and empower them to achieve their highest potential and independence
- Receiving assistance to ensure treatment compliance
- Being in an environment that helps them manage their condition more effectively.

The idea is off course not to institutionalise them or keep them in these facilities, but to reintegrate them back into society (where possible), whether it be back with family or to live on their own when they have accessed employment and achieved a satisfactory level of independence. It is therefore always important to try and work with the families to try and restore a bond with the service user and equip the family with the skills on how to deal with their relative with mental disability.

NORTHERN CAPE

Northern Cape was very different from Mpumalanga in terms of family dynamics – they seem to value family irrespective of whether a family member has a mental disability and do create a fairly supportive structure in a home environment, even when they are not completely equip with the necessary skills.

Establishing activity groups or protective workshops were strongly identified as a need, especially since most of the participants had no formal education (matric) and the general unemployment rate in the province is high.

The benefits of providing activity groups and protective workshop services include:

- Being involved in activities that would keep the service users occupied and stimulated, their ability to manage their condition can improve
- Attending to activities daily would prevent them from isolation and having the opportunity to socialize with others
- Participating in activities can improve their self-worth and self-esteem

- Participating in activities can facilitate independence
- Products made during activities or at a protective workshop will aid their income and improve their quality of life
- The community's attitude will change when they see that the service users are functional and productive members of their community and can contribute to society, ultimately reducing stigma
- There will be less strain on the family when the service user is in a structured environment which improves their ability to look after themselves

Concerns raised

A concern that was raised from both site visits was reports received of suspected fraud related to disability grants – where service users notice deductions from their grants and when enquiring about it at SASSA, it is said to be for airtime and electricity, whilst the service users never made such purchases. SASSA then issue the service user with a new SASSA card but does not reimburse them for the fraudulent deductions that occurred.

Loan sharks also appear to be problem, either encouraging service users to take out loans (using their SASSA account) or families exploiting the service user by taking out loans (using their SASSA account).

Some local hospitals in both provinces do only have 72 hour assessment wards (which is reported to not always be a conducive environment for treatment and care), but then experience major problems when needing to refer service users for specialised care, due to lack of beds at a tertiary hospital.

In Mpumalanga the lack of beds at tertiary care becomes increasingly challenging where service users who are ready for discharge, has nowhere to go since families want nothing to do with them. The hospital can't keep them as they need the beds but at the same time, discharging them means throwing them onto the streets, which may just result in a revolving-door syndrome.

In the Northern Cape, clinics operate on the integrated health care model, which may be a great approach to address the lack of mental health professionals, including psychiatrists, but creates a problem related to an increased volume of patients to be seen and thus increasing the waiting time. Service users specifically and clinic staff indicated that this is often the cause for non-compliance.

Conclusion

It has been a valuable experience to engage with the various communities and to give them space to voice their concerns, challenges and needs. Participants expressed their gratitude for being given the opportunity to part of SAMHAM and for the efforts being made to assist in addressing their needs, through the action plans developed and to be implemented.