



**SA Federation for
Mental Health**

Psychosocial Disability Awareness Month 2023

***“Shattering stigma: sparking conversations and
shifting attitudes.”***

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1. PSYCHOSOCIAL DISABILITY AWARENESS MONTH

Psychosocial Disability Awareness Month (PDAM) is celebrated annually in July. For 2023, the SA Federation for Mental Health (SAFMH) will be running the theme ***“Shattering stigma: sparking conversations and shifting attitudes”***, focusing on challenging and dispelling the stigma surrounding psychosocial disability (PD), with the aim of highlighting the need for persons with lived experience of PD to be at the forefront of anti-stigma programming as we work to shift ongoing, widely-pervasive negative attitudes towards PD.

In support of the theme, SAFMH will be highlighting the importance of having persons with lived experience share their stories, with the aim of inspiring compassion, trust and understanding. It is our hope that this year’s PDAM campaign will *shatter stigma by sparking conversations and shifting attitudes* towards PD in South Africa.

2. WHAT IS PSYCHOSOCAL DISABILITY (PD)?

PD involves barriers to full participation, caused by the ways in which a person might think, feel or interact with others (Mental Health Coordinating Council, 2021). To enable a deeper understanding of PD, we can relate it to two commonly used models of disability:

1. **Social model** – this model talks about *psychosocial disability*. The United Nations Convention on the Rights of Persons with Disabilities also uses the term *psychosocial disability*. The word is derived from a) ‘*psychology*’ (i.e. how people understand their experiences, emotions, feelings and the world around them), and b) ‘*social*’ (how people view persons with mental health conditions, and what their society deems to be ‘normal’). PD largely refers to the economic and social impacts that a mental illness may have on someone, for example their ability to earn money, purchase life necessities, or have relationships with family and friends. It describes the challenges experienced by a person that are due to their mental health condition, which affect their ability to participate fully in life.
2. **Medical model** – talks about *psychiatric disability*, and focuses on how medically-defined symptoms, related to a diagnosis, impact on a person, and how these symptoms may be treated.

PD is therefore not about giving the affected person a diagnosis. It is about the barriers and functional impacts a person with a mental illness experiences, with disability arising as they engage with social environments that hinder their sense of equality in comparison to other people (Government of New South Wales, 2020). Other barriers these individuals also face include stigma, discrimination and human rights violations, all of which undermine their dignity (WHO, 2015).

3. STIGMA

Stigma is defined as *“an attribute, quality, or condition that severely restricts or diminishes a person’s sense of self, damaging their self-worth, social connections and sense of belonging”* (Ault et al, 2017). The Lancet Commission’s report on Ending Stigma and Discrimination (Thornicroft et al. 2022) describes stigma as something that *“powerfully and adversely affects individuals, families, communities, and society, is persistent, and exists across cultures”*. It also states that *“stigmatisation can be seen as a complex multilevel social process that encompasses the elements of labelling, stereotyping, separation, status loss, and discrimination in the context of a power situation”*. This Lancet Commission report is the result of a collaboration of more than 50 people worldwide. It brings together evidence and experiences of the impact of stigma and discrimination and successful interventions for stigma reduction.

Stigma is one of the main barriers faced by persons with PD in South Africa today (Mahomed & Stein, 2017). It is a major cause of discrimination and exclusion, affects people's self-esteem, disrupts relationships and limits people's ability to socialise (WHO, 2020). Stigma can also prevent people from seeking the help they need. Stigma can lead to lost opportunities with regards to employment and education and can also hinder access to basic human rights and healthcare (Davies et. al 2021).

“In my family they used to include me in all decision making during family meeting or gatherings, but now I am always excluded in any gatherings or decision making. At times, they make decisions for me and this makes me feel as if I am incompetent person and that people do not believe in me anymore.”

– a mental health care user from Johannesburg

The American Psychiatric Association (2020) outlines other harmful effects of stigma, including:

- Reluctance to seek help or treatment
- People being less likely to adhere to treatment
- Social isolation
- Lack of understanding by family, friends, co-workers, or others
- Fewer opportunities for work, school or social activities
- Trouble finding housing
- Bullying, physical violence or harassment
- Health insurance that doesn't adequately cover the treatment of mental illness
- The belief that the person will never succeed at certain challenges or that they can't improve their situation

TYPES OF STIGMA

Self-Stigma

This is when persons with ID are aware of the negative stereotypes of others, agree with them, and turn them against themselves.



Stigma by Association

Refers to the attribution of negative stereotypes and discrimination to family members or staff working with persons with ID.



Public Stigma

This is the link between stereotypes, negative attitudes, and discrimination against persons with ID in society.



Systemic Stigma

Refers to policies and practices that work to the disadvantage of a stigmatised group, whether intentionally or unintentionally.



Source: The Lancet Commission on Ending Stigma and Discrimination in Mental Health

“Stigma and discrimination, throughout history, have exposed people with mental health conditions to its often-devastating consequences and has built an unwelcoming society where structures and behaviours forced people with mental health conditions to defend their humanity and value.”

- Charlene Sunkel, Founder and CEO of the Global Mental Health Peer Network and one of the authors of the aforementioned Lancet Commission.

The media is a powerful role player when it comes to perpetuating stigma, especially when they reinforce negative stereotypes that can bring harm to persons with a mental illness. These portrayals have often been negative, inaccurate or violent representations. Take the film, *Joker*, for example. A 2020 study found that viewing the film *"was associated with higher levels of prejudice toward those with mental illness."* The authors also suggested that *"Joker may exacerbate self-stigma for those with a mental illness, leading to delays in help seeking."* (American Psychiatric Association 2020).

Stigma is incredibly harmful, but it does not have to be inevitable. Evidence from high-and low-income countries suggests that anti-stigma interventions can change public attitudes for the better (WHO, 2022). The Lancet Commission (Thornicroft et al. 2022) reports that the most effective anti-stigma programmes involve people with lived experience as co-producers in all aspects of development, when target groups are consulted on programme content and delivery, and when programmes are sustained over the long term.

4. ANTI-STIGMA PROGRAMMES

According to the Committee on Science of Changing Behavioral Health Social Norms, anti-stigma programming *presents “factual information about the stigmatised condition with the goal of correcting misinformation or contradicting negative attitudes and beliefs”* (Committee on the Science of Changing Behavioral Health Social Norms et. al 2016).

A goal of anti-stigma interventions is usually to increase help seeking for mental health care (Thornicroft et. al 2022). We know that in South Africa, less than 1 in 10 people living with a mental health condition receive the care they need (Docrat and Lund 2019), so it is critical that we understand what an anti-stigma programme should look like and how we can best implement these so that we can begin to *shift attitudes* to ensure persons with PD feel included and are treated equally.

The Lancet’s global evaluation of ten large-scale anti-stigma programmes found that these programmes are more effective when persons with lived experience are involved in all aspects of developing the programme, when the people these programmes are aimed at are meaningfully consulted on the delivery and content of the programme and when these anti-stigma programmes are sustained over a long period of time. (Thornicroft et. al 2022).

The report outlines the key “hallmarks” of anti-stigma programmes, see the image below:

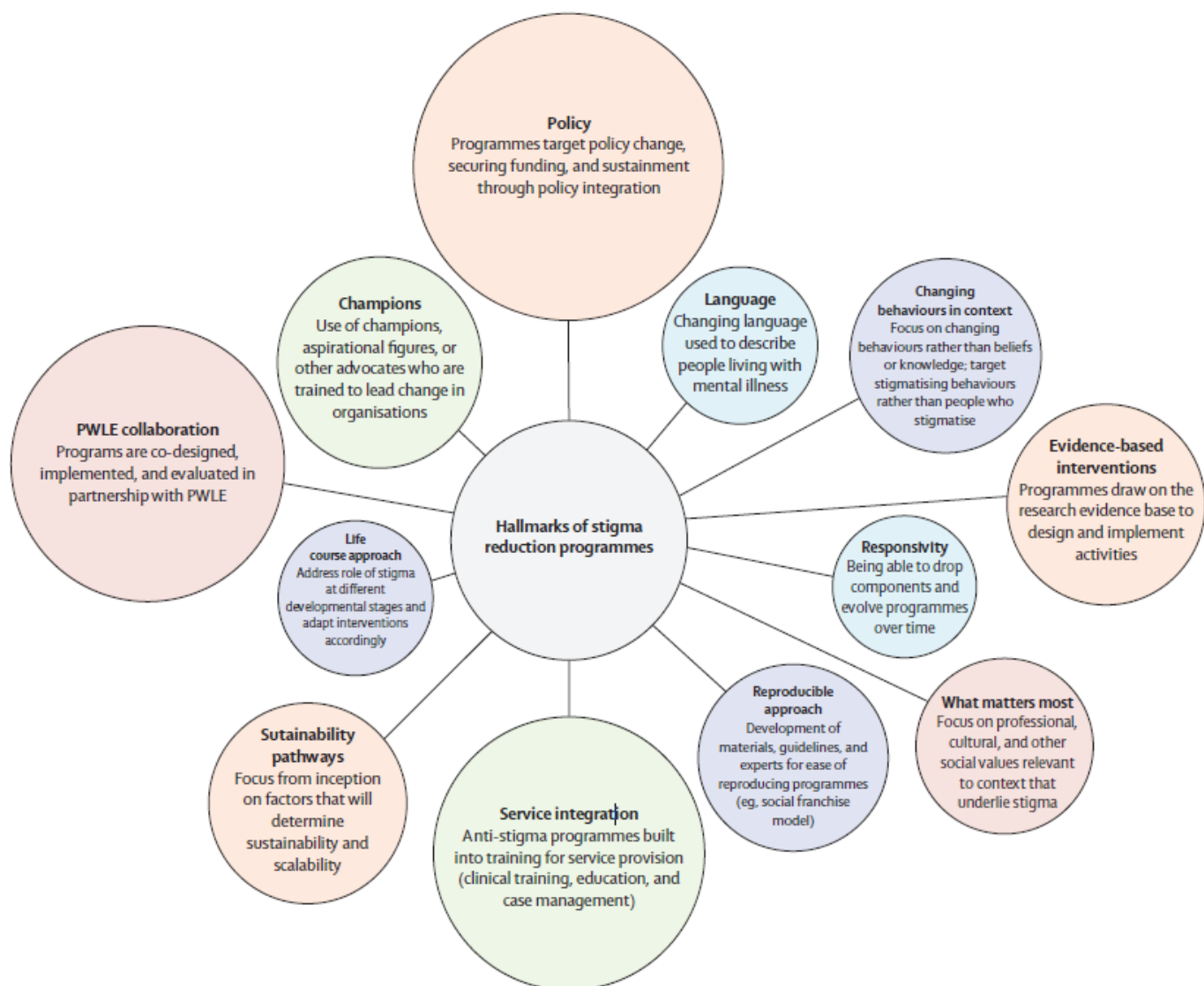


Figure 1: Key hallmarks of stigma reduction programmes

Balloon sizes represent the relative importance of key components and activities.

Some examples of anti-stigma programmes they shared include (Thornicroft et. al 2022):

- [**The Carter Centre Mental Health programme \(Liberia\):**](#) This programme targets journalists and promotes the involvement of people with lived experience in advocacy organisations and policy-making.
- [**Like Minds, Like Mine \(New Zealand\):**](#) One of the longest-running anti-stigma interventions, Like Minds, Like Mine is a public awareness programme aimed at increasing social inclusion and ending discrimination towards persons with lived experience of mental illness.
- [**Reducing Stigma among Healthcare Providers \(Nepal\):**](#) This programme is innovative in that it uses PhotoVoice, a visual narrative technique, to involve persons with lived experience when looking to reduce stigma amongst primary healthcare workers.
- [**Time to Change programme \(England\):**](#) The Lancet Commission describes it as one of the “most intensively researched national anti-stigma programme in the world.” It was a national campaign aimed at reducing stigma and discrimination.

Anti-stigma interventions do not always have to be years-long and costly. Small-scale cultural activities, like exhibitions, performances, festival can also reduce stigma (Thornicroft et. al 2022). From the evaluations, the Lancet Commission found that there were benefits to both multimedia online and in-person approaches to anti-stigma activities. They also found that using digital communication methods were very effective and could be important components in delivering anti-stigma campaigns (Thornicroft et. al 2022).

Persons with lived experience also shared that training was important, was along with peer support, having feedback provided and remuneration.

“Critical to pay people if possible. Sharing a lived experience is a vulnerable thing, and a skill. It should be paid in the same way other work should be paid.”

– a mental health care user from Norway

“Provide training and workshops to make it easier for me to reflect such as searching for my soul.”

– a mental health care user from Hong Kong

The report also found that anti-stigma programmes must be monitored and evaluated on a regular basis, right from the start, with key achievements and changes being documented. The authors argue that evaluations should not be done as a ‘tick-box’ exercise, but should rather done meaningfully to monitor how programmes are improving and having impact (Thornicroft et, al 2022).

Of all their findings, by far the most significant was that it is crucial for persons with lived experience to be involved in the planning, development, implementation and evaluation of anti-stigma programmes.

A great example of an organisation already doing work in this field is the Global Mental Health Peer Network. This international organisation is *for* and *run by* persons with lived experience. Not only do they build capacity among persons with lived experience, they also offer consultancy services to organisations looking to work with persons with lived experience, who ultimately are the experts when it comes to mental illness.

Whilst SAFMH acknowledges that the refreshed National Mental Health Policy Framework and Strategic Plan 2023-2030 includes plans to establish a national public education programme, which includes addressing stigma and discrimination towards persons with mental illness, there is no clear outline of any specific anti-stigma programming. We hold the view that the South African government needs to actively work on ensuring that there is sufficient funding for anti-stigma programming and that the planning, implementation and evaluation of these interventions should be done so in a collaborative, meaningful manner in close consultation with persons with lived experience of mental illness and NGOs working with these individuals, and that it should specifically also include contact-based education as part of its intended activities. Contact-based education involves people with lived experience interacting with the public, and sharing their stories to foster a level of trust and comfort (Committee on the Science of Changing Behavioral Health Social Norms et. al, 2016).

Additionally, we call on the media to consider their role in shifting attitudes regarding persons with mental illness. We would like to reiterate the call by the *Lancet Commission* for all media organisation to *“systematically remove stigmatisng content from their products”* (Thornicroft et. Al 2022) and instead use their platforms to promote positive attitudes towards persons with mental illness, with the aim of

reducing stigma. And it should not just be about including persons with mental illness in the media, but about *how* they are included. We recommend that those in media work closely with persons with lived experience, networks like the Global Mental Health Peer Network and NGOs operating in the mental health space to ensure the portrayal of mental health in the media is not purposefully or accidentally perpetuating negative stereotypes.

5. SPARKING CONVERSATIONS & SHIFTING ATTITUDES

“I have personally been very, very vocal about my struggles and how I overcame it. I believe that through heart-to-heart dialogue with people, you can communicate and help them understand.” – –
mental health care user from India

During World Mental Health Month 2022, SAFMH held a workshop focused on stigma with residents at the Talisman Foundation, located in Johannesburg. Talisman is a psychosocial recovery centre that supports approximately 200 people with PD. On the day, residents shared their experiences of stigma at work, from family and friends, as well as what they believe needs to happen for attitudes to shift. Some effects of stigma that were shared included:

- Isolation and loneliness
- Low self-esteem
- Self-stigma
- Not seeking help
- Job loss

Overall, the residents believed that stigma was related to a lack of understanding and misinformation of mental illness. They believe that education has a big role to play when it comes to reducing stigma.

“People judge, so educate them!”

– mental health care user from Talisman

During the planning for PDAM 2023, having open and honest conversations about PD was a theme that was strongly supported by our Mental Health Societies. Cape Mental Health said: *“We believe that open and honest conversations can play a significant role in promoting awareness and fostering a more accepting society. Much of the stigma around psychosocial disabilities are perpetuated by cultural beliefs and belief systems...People should have a more open and honest conversation about psychosocial disability. Not just highlighting the negative side of what is shown in the media or what is assumed.”*

Central Gauteng Mental Health Society said: *“We believe that open and honest conversations can play a significant role in promoting awareness and fostering a more accepting society.”*

Whilst we acknowledge that over the years attitudes towards PD have become more positive, and COVID-19 brought about an increased “openness” about the importance of good mental health, there is still a long way to go. SAFMH believes that the continued stigmatisation and resulting exclusion of persons with PD can be mitigated if we commit to designing meaningful anti-stigma programmes.

We have already seen global examples of anti-stigma programmes as outlined by the Lancet Commission, but our community-based organisations are also doing some great work using the same principles. Northern Cape Mental Health implements an anti-stigma programme that is aimed at shifting the attitudes of their community by encouraging their mental health care users to get involved in the running of the organisation. Social Worker, Charlene Hermanus, said that this includes running reception and welcoming new mental health care users. She says: *“We also have the Hartsfees festival where we expose our service users to a lot of people attending this festival. People coming to this festival buy the items made by our service users and they don't always know what our service*

users are capable of doing. Here they experience and see for themselves that they are not incapable or incompetent.”. Central Gauteng Mental Health are also proactive in this regard. They run an outpatient programme where they run awareness activities to educate communities about PD. They also host an annual talent show where their mental health care users share their talents with the local community.

6. CALL TO ACTION

“A lot still has to be done, but I learned sharing experiences is a journey of healing and helps destigmatise mental health problems.”

– a mental health care user from Johannesburg

We know that PD continues to be misunderstood, and stigma is one of the main reason for this. However, it we can bring about change, and it is therefore up to us to develop meaningful anti-stigma interventions that bring persons with PD’s lived experience to the forefront of programming, policies and stories.

SAFMH believes that stigma can be eradicated if we start by meaningfully **shifting attitudes** to psychosocial disabilities across all areas of society. This PDAM we call for:

- **Media** to consider their role in shifting attitudes regarding PD. Specifically, how their reporting could promote positive attitudes towards PD and prevent stigma and discrimination.
- The **public** to reflect on their attitude towards PD as this can go a long way in supporting more community inclusions for persons with PD.

We also call on the South African government to commit to their aims, as set out in the National Mental Health Policy Framework and Strategic Plan 2023 – 2030, and to establish a robust national public education programme that focuses on knowledge sharing and stigma and discrimination against persons with lived experience. In addition to establishing this programme, government should also implement widespread, detailed anti-stigma programmes that are developed in close collaboration with persons with lived experience and advocacy organisations, to ensure that the barriers faced in destigmatising mental illness are comprehensively addressed. We also continue to call for purposeful commitment from government to listen to the stories of persons with PD, to learn from these, and to utilise these learnings within areas such as policy development and implementation.

We also call on organisations working with persons with PD to commit to including their mental health care users in all aspects of anti-stigma policy and programming. We also ask these organisation to encourage persons with PD to share their experiences and to be proud of their stories, with the aim of inspiring compassion, trust and understanding. Storytelling has been shown to be an effective tool in terms of advocacy and reducing stigma and improving overall mental health care. It also goes a long way in ensuring the inclusion for persons with PD in all aspects of life (Ball, 2013).

There are a number of activities that will be undertaken by our Mental Health Societies during July. For example, Cape Mental Health will be focusing on *sparking conversations* in the workplace and encouraging their mental health ambassadors to share their stories of coping and adapting to a formal environment at their workplaces. They will also have a storytelling afternoon at one of their residential facilities.

In addition to sharing the PDAM campaign message far and wide, SAFMH will be running a storytelling workshop with persons with PD. The workshop will aim to share the structures and fundamentals when it comes to harnessing narratives, with the aim of providing persons with PD with the skills to share their stories and experiences with others.

The information shared in this concept note could also be adopted by stakeholders as part of press statements, infographics, and awareness and/or programmatic interventions that are devised as part of their contributions towards the July 2023 PDAM campaign.

REFERENCE LIST

- American Psychiatric Association, A., 2020. Stigma, Prejudice and Discrimination Against People with Mental Illness. [online] psychiatry.org. Available at: <<https://www.psychiatry.org/patients-families/stigma-and-discrimination>> [Accessed 30 May 2022].
- Ault, K. E., Juart, K. B., Ridgley, L. M., Satmare, G. A., Stephens, J. M., Stringer, S. A., & Williams, S. L. (2017). A fulcrum of change: From self-stigma to resilience. *Stigma and Health*, 3, (4), 315-324.
- Ball, R., 2013. When I Tell My Story I'm in Charge: Ethical and Effective Storytelling in Advocacy. SSRN Electronic Journal
- Committee on the Science of Changing Behavioral Health Social Norms; Board on Behavioral, Cognitive, and Sensory Sciences; Division of Behavioral and Social Sciences and Education; National Academies of Sciences, Engineering, and Medicine, 2016. Ending Discrimination Against People with Mental and Substance Use Disorders. [online] Available at: <<https://www.ncbi.nlm.nih.gov/books/NBK384914/>> [Accessed 1 June 2022].
- Deany, P., 2016. Psychosocial Disability: one of the most misunderstood areas of disability – Disability Rights Fund. [online] Disability Rights Fund. Available at: <<https://disabilityrightsfund.org/our-impact/insights/psychosocial-disability/>> [Accessed 6 June 2022].
- Docrat, S. and Lund, C. (2019) SA's 92% mental health treatment gap, UCT News. Available at: <https://www.news.uct.ac.za/article/-2019-10-10-sas-92-mental-health-treatment-gap> (Accessed: 04 June 2023).
- Government of New South Wales (2020). *What is psychosocial disability?* <https://www.health.nsw.gov.au/mentalhealth/psychosocial/foundations/Pages/psychosocial-what-is.aspx>
- Mahomed, F. and Stein, M., 2017. De-stigmatising psychosocial disability in South Africa. *African Disability Rights Year Book*, [online] pp.64-83. Available at: <<https://repository.up.ac.za/handle/2263/64698>> [Accessed 6 June 2022].
- Mental Health Coordinating Council (2021). Disability and psychosocial disability. <https://reimagine.today/what-is-psychosocial-disability/disability-and-psychosocial-disability/>
- National Mental Health Policy Framework and Strategic Plan 2023-2030. Available at: chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/<https://www.spotlightnsp.co.za/wp-content/uploads/2023/04/NMHP-FINAL-APPROVED-ON-30.04.2023.pdf>
- Rössler, W., 2016. The stigma of mental disorders. *EMBO reports*, 17(9), pp.1250-1253.
- Thornicroft, G. et al. (2022) "The Lancet Commission on ending stigma and discrimination in Mental Health," *The Lancet*, 400(10361), pp. 1438–1480. Available at: [https://doi.org/10.1016/s0140-6736\(22\)01470-2](https://doi.org/10.1016/s0140-6736(22)01470-2).
- WHO, 2015. World Mental Health Day 2015: Dignity and mental health information sheet. https://www.who.int/mental_health/world-mental-health-day/infosheet_wmhd2015.pdf?ua=1
- WHO, 2020. Social stigma associated with COVID-19. [online] Available at: <<https://www.who.int/publications/i/item/social-stigma-associated-with-covid-19>> [Accessed 2 June 2022].