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Exploring mental health support services for people with physical disabilities

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Background

It has been documented that 16% of the world's population has a disability, with a high concentration of this vulnerable minority living in the sub-Saharan region (World Health Organization [WHO] 2021). It is also reported that gaining access to healthcare within low- and middle-income countries (LMICs) remains a challenge (Vergunst et al. 2015). Persons with disabilities living in these contexts face a range of additional challenges, including inaccessible natural and built environments (McKinney & Amosun 2020) and discriminatory attitudes towards their disability within their communities (Hunt et al. 2018; Vergunst et al. 2015). All these factors affect their ability to access adequate and equitable healthcare.

In terms of mental health, it is estimated that one in eight people around the world are living with a mental health condition, predominantly anxiety or depression disorders (Institute for Health Metrics and Evaluation [IHME] 2020). Of great concern is that South Africa has a higher prevalence, with one in six adults presenting symptoms of anxiety, depression and/or substance abuse over 1 year (Herman et al. 2009; Shisana et al. 2024). Although accurate data in South Africa on adolescents living with mental health conditions are limited, it is estimated that, at any given time, a significant percentage of adolescents across the sub-Saharan region are dealing with depression (27%), anxiety (30%) as well as behavioural and/or emotional problems (41%) (Sorsdahl et al. 2023).

The WHO declares that mental disorders are the major cause of years lived with disability (one in every 6 years), which carries significant economic consequences globally (WHO 2021). Moreover, persons with disabilities are at twice the risk of developing health conditions, such as depression, in comparison to persons without disabilities (WHO 2021).

South African context

South Africa became a democracy for the first time in 1994, having overcome the apartheid government, and that brought a strong focus on individual rights and being able to live free from discrimination in an inclusive society. This encompassed disability-related policy and legislation, including the ratification of the United Nations Convention on the Rights of Persons with Disability (UNCRPD) in 2007 and the launch of the White Paper on the Rights of Persons with Disabilities in 2015 (Department of Social Development [DSD] 2015). However, over the last few decades, many challenges to effective service delivery have prevailed, including a lack of collaboration among government departments and the disability sector; insufficient gathering of disaggregated data on disability; slow service delivery; inadequate budgets; and, a lack of disability awareness and training among government staff and civil society, especially at grassroots level (McKinney, Schneider & McKinney 2024b). Furthermore, the legacy of apartheid continues to cause racial and economic divisions, and South Africa remains one of the most unequal countries globally (Hino et al. 2018; Vergunst et al. 2015). On the whole, persons with disabilities experience exclusion from society and denial of opportunities across most spheres of life, including access to basic services (such as healthcare and education), employment opportunities in the labour market (both informal and formal) and moving independently within the built environment. From an advocacy and/or political perspective, most persons with disabilities are unable to contribute to decision-making processes that govern their own lives. Together, these factors have a significantly detrimental effect on their citizenship and everyday quality of life (McKinney & Swartz 2021; McKinney, Swartz & McKinney 2020; Ned et al. 2024; Watermeyer & McKinney 2022).

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Impact of COVID-19

The extent of the underlying inequalities really came to the fore during the coronavirus disease 2019 (COVID-19) pandemic. Research on the lived experience of persons with disabilities, particularly those with physical and/or mobility impairments, highlighted how they were disproportionately affected by the stress and trauma related to the pandemic and struggled with prevailing and previously unconsidered challenges (Lund et al. 2020; Ned et al. 2024).

A major issue was the experience of increased isolation, particularly through diminished access to transport and the built environment. At the outset of the pandemic, a national lockdown was declared to stop people from going outside and socialising. However, as restrictions eased, people with physical disabilities still found it difficult to venture outside. Part of this was linked to the stigma surrounding their disability, with some community members believing that they were contagious. Furthermore, many still felt vulnerable and not ready to go outside because of their more precarious health conditions, as well as the difficulty in using personal protective equipment (PPE) (Ned et al. 2024). Another key finding was their escalated reliance on family members for all daily activities. Sometimes this reliance was a result of regular caregivers not being able to travel because of lockdown conditions. In other instances, day centres were forced to close, and so children with physical disabilities had to be looked after at home, causing immense strain on family resources and relationships.

Additionally, persons with physical disabilities were subject to discriminatory triage policies, and excluded from life-saving healthcare such as hospital admission, intensive care unit (ICU) bed access and ventilator access, through to not being able to access the personal care they required because of social distancing (McKinney, McKinney & Swartz 2021). This led to feelings of being 'devalued' by society and questioning one's worth (Watermeyer & McKinney 2022). Besides being fearful of contracting COVID-19, struggles with anxiety and depression increased for many persons with physical disabilities as they felt helpless, lonely and a burden to their families (Ned et al. 2024). Finally, persevering without receiving any mental healthcare services increased the precariousness of persons with physical disabilities. In other words, for those with pre-existing mental health disorders, poor management of their disorders generally risks negative treatment results for both their mental health and physical conditions (Pettinicchio et al. 2021; Theis et al. 2021).

The Department of Health (DoH 2023) identifies that the COVID-19 pandemic, which it describes as a physical condition, generated mental and emotional anxiety among a large number of people. Persons with physical disabilities were particularly affected for reasons relating to both their impairment and their physical environment. In a broader context, however, Shisana et al. (2024) argue that the shared societal experience of the pandemic generated more awareness regarding mental health. They suggest this provides an opportunity for increased dialogue to address and transform previous stigma surrounding mental health issues.

Conversation

The author of this community paper is a person with a physical impairment. He is a quadriplegic as a result of an accident three decades ago and has been using a motorised wheelchair since that time. Having been involved with many projects for persons with physical disabilities at the grassroots level over the years, he felt a growing concern for the need for mental healthcare support, as highlighted during COVID-19. He reached out to Prof. Swartz and Prof. Watermeyer to seek their input and experience on the situation. Here, they collaboratively explored possible options for persons with physical disabilities, specifically counselling and psychotherapy sessions. Unsurprisingly, from the outset, the range of options looked rather bleak. This was because of the challenges of inaccessible environments, the lack of personal assistance (including the availability of family members and caregivers), as well as the limited number of mental healthcare services available within South Africa.

However, the discussion continued, and a particular comment from Prof. Swartz generated two broad themes that inform the rest of this article. He said:

> 'I guess the main thing is to see what is there … find out what can be used and made accessible to people with physical disabilities … and then explore what else is out there, what is new… And try and build upon that.' (Discussion with Profs Swartz and Watermeyer, 19 March 2023)

These themes are loosely described as 'What's available' and 'Building on new and other programmes'.

The following sections expand these themes, reflecting on the National Mental Health Policy and Strategic Framework of South Africa 2023–2030 (MHPFA) and current services available, including professional, non-professional, state, as well as non-governmental organisation (NGO)-driven, highlighting prevailing challenges for persons with physical disabilities. Thereafter, possible strategies and recommendations are suggested. Comments from the conversation with Prof. Swartz and Prof. Watermeyer are referred to throughout the rest of the article.

What is available

When discussing available services, Prof. Swartz and Prof. Watermeyer quickly identified that the shortage of professional services, and in particular, specialist therapists and programmes, was an ongoing problem for most of the population and hospitals out there.

Professional services

The MHPFA (DoH 2023) describes psychological rehabilitation as follows:

> Mental health services that bring together approaches from the rehabilitation and the mental health fields, combining pharmacological treatment, skills training, and psychological and social support to clients and families in order to improve their lives and functional capacities. (p. 11)

The new MHPFA sets out to strengthen the national health system towards achieving comprehensive service delivery regarding mental healthcare, promotion, prevention, care, treatment and rehabilitation (DoH 2023). This strengthening is sorely needed. The WHO Organisational Global Health Observatory Data Repository documents that currently there are only 1.52 psychiatrists per 100 000 people in South Africa (Janse Van Rensburg et al. 2022). Within public hospitals offering mental health services, 30% do not have a clinical psychologist, and only about 50% have a psychiatrist (Nguse & Wassenaar 2021).

Research has shown that formal community mental health services have a significant and positive impact at the community level (Thornicroft et al. 2016). These services include group homes and halfway houses, as well as day-care services, such as support groups, home-based support care and protective workshops. These services are vital to ensuring that mental healthcare users who have been discharged from inpatient facilities can integrate back into the community effectively (Shisana et al. 2024; Sorsdahl et al. 2021). A specific advantage of community healthcare centres is that they provide a more holistic recovery approach. More specifically, they broaden the treatment model from focusing predominantly on clinical recovery (symptom remission through specialised psychiatric services) towards personal recovery. This incorporates aspects of improved functioning, community and/or social inclusion, family support, access to employment, alongside remission of symptoms as indications of recovery.

A key drawback, though, is that national policy guidelines for the licensing of residential and/or day-care centres, while gazetted by the National Department of Health (NdoH) in 2018, have not yet been finalised. Consequently, there are concerns that the standards required would have to be the same as hospital standards, and this would not be achievable within community-based healthcare facilities (Robertson, Moosa & Jeenah 2021). This ties in with comments from Prof. Swartz regarding how some services are held up by bureaucratic and/or administrative processes. He and Prof. Watermeyer also suggested that these are issues where the disability sector could get involved and lobby for, specifically towards making future mental healthcare programmes inclusive and sustainable.

According to Sorsdahl et al. (2023), available data indicate that there are 355 community-based mental healthcare facilities across South Africa. These are licensed in line with Regulation 43 of the *Mental Health Care Act, 2002*. However, besides that, there is little data in terms of the NGOs, the number of patients, the cost per patient and/or subsidies received by the Departments of Health (DoH) and/or DSD. The limited number of community health programmes that are available must continue to be strengthened, as such programmes are integral to providing a link between (inpatient) hospital care and community-based (outpatient) rehabilitation, especially those that offer 1 month to 3 months' residential psychosocial rehabilitation programmes. These programmes also involve life skills training and help users develop healthy lifestyle patterns and recreational goals (Sorsdahl et al. 2023).

However, having so few formal community healthcare centres has resulted in a stronger focus on using medication to treat healthcare issues; that is, the focus is much more on clinical recovery as opposed to personal recovery. In turn, this lack of support at the community level has created a situation where a quarter of inpatients who are discharged from the hospital are returning and being readmitted into the wards for treatment within 3 months. Moreover, these readmissions come at a cost of 18.2% of the public health system budget, which is allocated for healthcare (Sorsdahl et al. 2023). Additionally, findings from the last Stress and Health Survey, conducted from 2002 to 2004, suggested that treatment was received by less than 30% of persons with moderately severe disorders and less than 25% of those with mild disorders (Shisana et al. 2024). Besada, Docrat and Lund (2021) indicate a decline since then, estimating that the treatment gap has widened to over 90% for those with epilepsy, intellectual disability and mental disorders. While the above has described the shortage of community health facilities, it still has not yet accounted for prevailing obstacles in the natural and built environments including inaccessible public transport systems, which presents a further challenge for persons with physical disabilities in accessing adequate mental healthcare services.

The notion of linking to other specialised services arose while the author was talking about finding counselling for a fellow quadriplegic who became paralysed at a young age and grew up in poor socio-economic circumstances. He had lost two older brothers to gang-related violence and had experienced a substantial amount of trauma in his life. Prof. Watermeyer pointed out:

> 'I can think of one facility, The Trauma Centre for Survivors of Violence and Torture in Woodstock (area of Cape Town) – you need to apply and write a letter of motivation – then of course see how accessible it is – but it is an option, they could really help.' (Discussion with Profs Swartz and Watermeyer, 19 March 2023)

This generated further discussion in two areas, firstly, how many persons with disabilities experience(d) some kind of trauma related to their disability, which has impacted them long-term psychologically (Kagan, Itzick & Tal-Katz 2018). Secondly, exploring access to mental healthcare support through other channels which may not be thought of straightaway.

Besides government services, numerous established NGO-driven programmes address mental healthcare. The organisations are reliant on external funding and operate from a national level down to more regional and local initiatives; they include the South African Depression and Anxiety Group (SADAG), Hotline, Lifeline, South African Federation for Mental Health (SAFMH), Family and Marriage Society of South Africa (FAMSA), Cape Mental Health, HEAL South Africa, The Foundation for Professional Development, CIPLA Mental Health Helpline and others. Their services are generally low-cost or free of charge and include specialised therapy, direct one-on-one telephone counselling (including suicide and crisis lines), educational resources and training, conducting online support groups, advocating for increased mental healthcare services and rights, among others. Despite the number of organisations, they cannot keep up with demand and funding for services and trained professionals remains a constant concern.

Building on new and other programmes

Extending from Prof. Watermeyer's comment about tapping into other specialised services – in this section on exploring other mental healthcare and/or support programmes for persons with disabilities – we focus on peer group training, which is quite well-known in the disability sector, as well as on a community-driven approach.

Non-professional therapy peer group training

Peer group training (PGT), as a form of non-professional therapy, has been shown to provide many positive impacts on the daily life of persons with physical impairments, including their independence within society (Kumurenzi et al. 2023).

The idea behind PGT is that a person receives advice and support from a group of their peers who have the same disability as them, for example, wheelchair users. Participating in PGT often takes place in day workshops or camps, and is led by a group of mentors (with the same disability) who have gained experience in living with a particular condition (Srubarz-Stach, Rutkowska & Dabrowska-Galas 2024). Sessions may cover various aspects of everyday life facing persons with disabilities, including practical sessions, such as how to manage everyday activities in a wheelchair. These activities typically involve how to transfer from a wheelchair onto a bed or into a car; how to get back into one's wheelchair if one falls out of it, et cetera. Other sessions may involve discussion around life skills or more intimate subjects. Sessions occur in groups or in a one-on-one buddy type scenario where topics may cover how to apply for and behave appropriately in a job interview, to more sensitive subjects, such as bladder and/or bowel management, sexuality or parenthood. Taking part in PGT has proven to be beneficial for many on a range of levels (Best et al. 2016; Kissow 2015). To begin with, individuals get to be around others dealing with the same everyday disability-related challenges. They get to share their challenges, fears and ideas and learn from others who have been through similar experiences. Sharing their stories with people in the same situation also helps to validate emotions that many may be dealing with about their disability. Often these emotions are not easy to talk about to persons without disabilities, even though they may be very close (such as family members) and well-meaning; however, they simply cannot relate as they are not going through the same daily embodied experience (Watermeyer & McKinney 2022).

Outcomes of PGT are generally positive and generate increased self-esteem and confidence (Steinberg et al. 2023; Srubarz-Stach et al. 2024). Encouraging themes for adults with physical disabilities have emerged from the literature, such as 'getting my life back' and 'I can do it too'. They also expressed experiencing better quality of life through a heightened sense of autonomy and social inclusion, often extending to sport and recreational activities (Ouellet et al. 2022; Pellichero et al. 2020). Such outcomes align with the goals of the UNCRPD in terms of increasing independence and participation of persons with disabilities in society (McKinney et al. 2024a), along with the aims of the MHPFA in terms of improved well-being and mental health (DoH 2023).

A number of organisations for persons with disabilities (OPDs) and their members are involved in peer group support initiatives. These include the Quad/Para Association of South Africa (QASA), the National Council of and for Persons with Disabilities (NCPD), the Rachel Swart Fund (RSF) and the Rehab Skills Lab, to name a few. Some of these OPDs also provide ongoing support to their members in a range of areas. For example, QASA services include assistance in daily living, that is, accessing disabled parking discs, assistive devices, driving lessons and provision of healthcare products when returning home from a hospital or rehabilitation facility.

Most research has focused on the benefits to adults with physical disabilities, especially wheelchair users. However, emerging research suggests that PGT at paediatric level has also been effective in lessening challenges to participation, as was found in research involving children and adolescents with cerebral palsy and spina bifida (Ouellet et al. 2022).

Other organisations, like the Shonaquip Social Enterprise (SSE), are alert to the stresses that family members of persons with disabilities experience. Through their Champions of Change Trust, the SSE offers education, networking and support to parents of children with disabilities to help them overcome the physical and emotional isolation that many of them endure (Trafford et al. 2021). A key strength of the SSE's approach was creating a dedicated app for parents. Using the app not only provides parents with a platform to share ideas, resources and support as and when they have access to data, but it also enables the network to reach right across South Africa. Additionally, the number of parents who have joined has increased rapidly and significantly, which has also given strength to their collective voice (Trafford et al. 2021). Overall, the support provided and shared has substantially enhanced the mental well-being of the parents (and/or caregivers), which in turn, has a positive impact on their children with disabilities and other family members (Rakap & Vural-Batik 2024).

In that sense, the emergence of virtual platforms, such as Zoom and Google Meet, for example, was the one outcome of the pandemic that was welcomed by persons with physical disabilities. Utilising these platforms meant they could overcome barriers to connecting with others without leaving their home. This gave rise to many online support groups that offered advice and a place to share and receive much-needed support. These online platforms also offer great potential for telerehabilitation services, including one-on-one consultation and group therapy sessions (Ned et al. 2024). It is important to note, however, an underlying inequality regarding access to virtual platforms, as many persons with physical disabilities living in poor socio-economic circumstances do not have access to technological devices and/or data.

Finally, a recurring issue is that in-person PGT services are generally urban-centred, and while some programmes extend to rural areas, such as RSF promoting independence through teaching wheelchair repairs, among others, there remains (as reiterated by Prof. Swartz) a dearth of adequate mental healthcare services away from the cities (Rall & Swartz 2023; Visagie & Swartz 2018).

Informal community healthcare services

Sorsdahl et al. (2023) suggest that the establishment of informal community healthcare services would greatly improve access to healthcare and help reduce the treatment gap significantly (2023). This approach involves training nonspecialists to be able to confidently identify and refer people in the community who they think would benefit from mental healthcare services. These 'nonspecialists' would comprise service providers already established within the community and include teachers, police, community healthcare workers and community members who provide peer support services. This approach would incorporate working with religious and traditional healers, who are often the first contact for persons struggling with mental health issues. The literature reveals that in some areas, up to 30% of people have consulted a traditional healer before seeking advice from anywhere else (Nortje et al. 2016; Sorsdahl et al. 2023).

This community-based healthcare approach ties in with the Inter-Agency Standing Committee (IASC) Guidelines on Mental Health and Psychosocial Support, as well as the WHO Optimal Mixed Mental Health Services Model (WHOMHS). The main goal of the IASC guidelines is to assist humanitarian aid stakeholders in collaborating to design and establish social support systems to protect and sustain mental health and well-being in times of crisis (IASC 2008). The foundation of the WHOMHS is that most healthcare needs can be treated with appropriate self-care, community support structures and primary healthcare services. It also acknowledges the importance of specialist psychiatric care, but that this should only be allocated for complex and severe cases (WHO 2007).

Essentially, these pyramid-structured models both suggest shifting the focus away from specialist institutionalised care (which is most costly but less frequently needed) towards increasing and capacitating community-based mental healthcare services (which are less costly but most in demand). The underlying notion is that creating a bottom-up approach, that is, addressing mental health predominantly at grassroots, primary healthcare level, will create a healthier society overall and help mitigate the need for specialised psychiatric services at institutional facilities (Shisana et al. 2024).

The way forward

Going forward, both Prof. Swartz and Prof. Watermeyer emphasised that, besides collaborating with other initiatives, current systems must be improved. To develop a comprehensive and effective mental healthcare service for persons with physical disabilities, far greater state investment and spending are needed for developing accessible infrastructure and facilities, as well as training and upskilling of staff in disability-related awareness and care. This ties in with the MHPFA, which includes prioritising mental health as a critical component of general healthcare (with increased budget); shifting focus from hospital-based care towards primary healthcare; and implementing collaborative systems at the primary/community care level, including increased access to specialist care services (Shisana et al. 2024).

Addressing the area of producing more mental healthcare professionals, Shisana et al. (2024) report that despite a significant number of undergraduate students specialising in psychology, only 5% of these will progress to master's level. This is because of a current limitation set by the Health Professions Council of South Africa (HPCSA) on how many master's students are allowed to enrol in higher education institutions (HEIs). Removing this limitation, coupled with increased funding for public sector posts for registered counsellors, would significantly increase the pool of psychotherapists. Additionally, the inclusion of more bridging programmes at HEIs, as is offered by the University of KwaZulu-Natal (UKZN), will enable mid-level workers to become registered counsellors after a year or two of study. In conversation, Prof. Swartz made the important point that the training of future healthcare professionals (as well as the design of training programmes) should include persons with disabilities as educators and experts in their own lives (Harvey & Swartz 2024; Swartz 2018). This also extends to their families and member organisations (OPDs) and falls in line with the motto of the disability movement, 'Nothing about us without us' (Stone 1997:2).

A pivotal strategy of the MHPFA is the establishment of a district mental health (DMH) team throughout all 52 districts of South Africa (in 2023, there were only 14 districts with DMH teams). This would enhance community-based skills development via clinical mentoring, improved quality and training, and also enable (although limited) access to additional specialist services (Shisana et al. 2024).

Furthermore, Prof. Watermeyer's point on linking with other services, and the positive benefits of PGT for persons with physical disabilities, strongly promotes collaboration between regional OPDs and mental healthcare NGOs such as SADAG, SAFMH, FAMSA, among others. They could also partner with DMH teams (and/or other local state services) to develop cross-cutting, tailor-made programmes that respond directly to the support needs of persons with disabilities. This would create inclusive community-based mental healthcare services that are culturally appropriate and accessible to all other minority groups (e.g. the elderly), particularly in rural areas. These programmes will also provide platforms for training of professionals and 'nonspecialist' workers in the community on basic counselling interventions, as well as screening, detection and referral of complicated cases that need specialist treatment. Development of programmes should also involve the Department of Cooperative Governance and Traditional Affairs (COGTA) and the South African Local Government Association (SALGA) to assist collaboration with traditional healers and also address negative community attitudes towards disability.

As described earlier, telerehabilitation services offer major opportunities to enhance treatment and therapy for persons with physical disabilities (and other minorities who struggle with accessibility or mobility). Collaborations, as well as lobbying from OPDs and NGOs, could support the provision of data by the state (and other organisations) for those in poorer socio-economic circumstances. One option is to provide a subsidy for access to data for persons with disabilities, and/or their caregivers, to enable them to access mental healthcare support. Another feasible possibility is linking to networks such as Giga, which is a joint UNICEF and International Telecommunication Union (ITU) education initiative aimed at creating virtual hubs across the globe so that every school can connect to the Internet. This would provide a platform not only for distance learning but would potentially give persons with physical disabilities access to a range of mental healthcare support services worldwide.

Finally, in terms of prevention, access to programmes that offer personal care assistance to persons with physical disabilities, and/or relief care to their existing caregivers, would go a long way to reducing levels of anxiety and depression caused by feelings of dependency and being a burden to others, especially family members.

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