

'Those most at risk are least likely to be counted'



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Introduction

Globally, the World Health Organization (WHO 2022) estimates that 1.3 billion individuals (16% of the world's population) live with significant disability underscoring the need for health equity for persons with disability to be prioritised as a global health objective. Of these 1.3 billion individuals, approximately 80% reside in low- and middle-income countries. In the South African context, a disproportionately high percentage of people with disabilities live in rural and remote areas (Couper 2002). Access to psychological services for individuals with disabilities in these regions is severely limited. The challenges faced by this population are consistent with those identified in the literature (Couper 2002; Morris et al. 2021; Rall & Swartz 2025; WHO 2022) and include: insufficient psychological staffing within the Departments of Health and of Education, inadequately developed infrastructure in health facilities for counselling and assessment, a lack of validated assessment tools and research tailored to this context – particularly given the educational challenges faced by many rural children with disabilities. Furthermore, there is a notable scarcity of specialised or adequately staffed inclusive education services. Geographic distance, a lack of accessible transport, the additional financial burden of transportation, and the limited economic resources of most families, significantly hinder access to care and education exacerbating the inequities in service provision.

Research on the prevalence of disability and the monitoring of access to appropriate care and services are particularly challenging in rural areas, where long distances, poor infrastructure (both in terms of roads and facilities), limited access to information technology and the urban-centric focus of universities hinder effective data collection and research.

It is within this context that the author wishes to acknowledge Professor Swartz. His substantial contributions to the author's professional development – as an academic, teacher, mentor and supervisor – are deeply appreciated. His work in the field of disability studies, both within South Africa and the broader African context, has significantly advanced knowledge in this area through research and publication. His efforts have highlighted the needs of individuals with disabilities, informed policy and evaluated interventions, by collaborating with people living with disabilities, thus supporting, enabling and encouraging further research in this field, as evidenced in this publication.

Prevalence of disability

According to Statistics South Africa (STATSSA 2024), the national prevalence of broad disability was reported as 15.7%, with urban and rural areas showing comparable rates of 15.2% and 16%, respectively. In northern KwaZulu-Natal, the reported prevalence was slightly lower at 15.4% for broad disability and 4.2% for severe disability. However, within the three districts comprising northern KwaZulu-Natal, the most remote, most impoverished and predominantly rural district was reported to have the lowest disability prevalence: 11.1% (broad) and 2.5% (severe). These findings are inconsistent with both the local experience of service providers and broader epidemiological expectations, raising concerns regarding the validity and reliability of the data in accurately reflecting the burden of disability in underserved regions.

Such inconsistencies highlight a critical issue in health systems planning and resource allocation, which often rely heavily on national statistics. When prevalence data underestimate the true magnitude of disability, particularly in marginalised, rural populations, the needs of persons with disabilities risk being rendered invisible in policy and practice. This phenomenon aligns with what has been described as the 'inverse data law' – those most at risk are often the least likely to be counted. Resources are allocated according to numbers calculated in official reports. It illustrates the need to accurately measure the magnitude of people with disability within health information

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systems or risk the needs of persons with disability becoming invisible and underprioritised. As the WHO (2022) has noticed, underdiagnosis and under-reporting are key contributors to the persistent underestimation of disability prevalence globally (WHO 2022).

Earlier studies offer alternative perspectives. For instance, Couper (2002) conducted a prevalence study in the same rural district and reported rates of 60 per 1000 in children under the age of 10 years living with disabilities. These included 17 per 1000 with mild intellectual disability, 10 per 1000 with cerebral palsy, 10 per 1000 with hearing loss, 10 per 1000 with moderate to severe intellectual disability and 4 per 1000 with seizure disorders. Such figures underscore the likely underreporting in official statistics. International data corroborate this concern. An epidemiological study in the United States found that 1 in 3 adults in rural communities lives with at least one disability, with approximately 1 in 12 reporting three or more disabilities (Zhoa et al. 2024). These findings reinforce the need for improved disability surveillance, especially in low-resource settings, and underscore the ethical imperative to ensure the inclusion of persons with disabilities in health information systems and policy frameworks.

Professor Leslie Swartz has emphasised the ethical responsibility of inclusive and accountable research practices. Accurate prevalence measurement is not only a technical necessity but also a matter of health equity and social justice.

Context

The author currently holds a clinical psychologist post, involved in the planning, development and delivery of psychological and mental health services in the northern region of KwaZulu-Natal, South Africa. The position is based at a developing tertiary-level public hospital, which functions as a regional referral centre and forms part of an integrated health system. A significant component of service delivery targets individuals with disabilities, including intellectual, physical, and neurodevelopmental disabilities, as well as those experiencing functional impairments associated with mental and physical illness.

The scope of services encompasses psychological assessment, psychoeducation and psychotherapy. In addition, the role involves facilitating access to educational opportunities, social services and disability grants. The role also encompasses collaboration with justice and welfare systems, contributing to a multidisciplinary, intersectoral model of care. Academic partnerships have been established with the Centre for Research and Health Systems at the University of KwaZulu-Natal, and further formal collaboration is being pursued with the university's Department of Psychiatry.

The tertiary facility provides services to a catchment area comprising approximately 3 million people, encompassing three health districts in northern KwaZulu-Natal (STATSSA 2024). The regional health infrastructure includes 2 referral hospitals (1 general hospital and 1 specialising in maternal

and child health), 15 district hospitals, 3 community health centres (CHCs) and a network of primary health care (PHC) clinics.

The mental health workforce in the region includes 10 clinical psychologists at the tertiary-level, three additional psychologists based at district hospitals, one community service psychologist, and three registered counsellors (based at the CHCs). The psychiatric team comprises two psychiatrists, one psychiatric registrar and several psychiatric medical officers. A regional mental health team includes an occupational therapist, a social worker and a psychologist. Each district is supported by a mental health coordinator, and there are a number of mental health nurses across the region, nine of whom have received specialist training in child psychiatry. Multidisciplinary mental health teams are variably structured, staffed and resourced across tertiary, district, and primary care levels. This reflects the evolving development of integrated mental health services within the public health system.

The journey

It is the questions one asks and seeks to answer that challenge their assumptions, guide their actions and give direction. One such question was posed to the author by Professor Leslie Swartz, then Clinical Director at the University of Cape Town clinical psychology training programme: 'What is the role of a clinical psychologist in South Africa?' This question was the topic of the entrance essay written during the selection process for the clinical psychology programme. This question has provided an ongoing thread during the author's professional life. It was the year 2000, South Africa was emerging from the social and economic injustices of apartheid. The discipline of psychology, like many other sectors, was confronting its role in a society marked by structural inequality and historical injustice.

The author's clinical training under the leadership of Prof. Swartz was intellectually broad, grounded in psychoanalytic thought, yet integrative in its orientation, drawing on diverse therapeutic modalities within the overarching framework of public mental health. Clinical exposure spanned the life course and included individual, family, and system-based interventions. Training placements occurred across a range of service contexts including psychiatric and general hospitals, community health clinics and partnerships with non-profit organisations. The assessment and intervention related to intellectual disability and learning disabilities, neuropsychological assessment in the context of acquired and degenerative neurological conditions were learnt. This training experience was intellectually and professionally formative, anchored by the foundational question of what it means to be a clinical psychologist in South Africa.

Professional roles and identity are shaped by context. The author's early career spanned roles in urban-based private

practice, work with non-profit organisations (notably Cape Mental Health), and ultimately, public sector service delivery. It was through the author's involvement with the Cape Mental Health Sexual Abuse Victim Empowerment (SAVE) programme that the focus of his or her doctoral research emerged.

Under the supervision of Professor Swartz – by then based at Stellenbosch University – the author pursued a PhD focused on the forensic psychological assessment of people with intellectual disability who had experienced sexual abuse. The study addressed issues of access to justice and the utility of the psychological assessment of adaptive functioning, in informing expert testimony in legal proceedings. This work foregrounded questions about disability, vulnerability, and the interface between clinical psychology and the legal system.

The author graduated with his or her PhD at the end of 2017. By mid-2018, the author transitioned from a comfortable public sector job working in child and adolescent mental health in Cape Town to a role focused on the development of mental health services in northern KwaZulu-Natal. This region, while rich in natural beauty and biodiversity, encompasses some of the most socioeconomically disadvantaged and rural districts in South Africa. The opportunity marked a pivotal shift – an extension of the core professional question posed nearly two decades earlier, now applied in a vastly different and under-resourced context.

The process

Growth of staffing and skills development

In 2018, psychological services in the regional health system were markedly underdeveloped. At the time, there were only two psychologists at the general (tertiary) hospital and none at the affiliated mother and child hospital. Among the 15 district hospitals in the region, only 2 employed permanent psychologists and 2 had community service psychologists.

Initial efforts focused on relationship-building and collaboration with some key stakeholders: the three district mental health coordinators, the medical managers of the district hospitals and Red Cross Air Mercy Services in providing transport for outreach. Outreach visits and capacity building workshops began with health professionals working in mental health at the district hospitals. The aim was to identify and build a mental health team at each hospital. This included medical officers, mental health nurses, occupational therapists, social workers and psychologists and varied from site to site. Research collaboration with University of KwaZulu-Natal (UKZN) Centre for Research of Health Systems began a process of implementation of the Mental Health Integration programme (MhINT) in one of the district hospitals and their clinics. The programme focused on a systemic integration of common mental health conditions into the PHC system with a focus on depression, anxiety, and the link of mental health to non-adherence in chronic conditions.

In response to the increasing costs of medico-legal claims for damages related to perinatal management, the Department of Health in KwaZulu-Natal designated

centres of excellence targeting cerebral palsy care. There was recognition of the importance of mental and psychological health in the care of people with cerebral palsy and their families and of the underdevelopment of psychological services in the region. This resulted in increased staffing of the psychology department from two to seven psychologists in early 2020.

The emergence of the coronavirus disease 2019 (COVID-19) pandemic posed substantial challenges. Psychological services adapted to the support of frontline workers and bereaved families. Mindfulness-based interventions and online individual and group therapy interventions were developed to address trauma, grief, moral injury and burnout. The pandemic period significantly heightened institutional awareness of mental health.

Psychological services were reintroduced at the mother and child hospital through voluntary deployment of two psychologists from the general hospital team. This catalysed the filling of the existing posts, and the final vacant post at the general hospital was filled, resulting in a 10-member team.

Between 2019 and 2020, child psychiatric nurses were trained in the region through initiatives of the provincial Department of Health. While attrition has occurred because of retirement, death and career changes, the remaining cadre of nurses continue to contribute meaningfully to child and adolescent mental health care.

Between 2022 and 2024, the National Health Insurance programme supported the appointment of three registered counsellors and the establishment of a regional mental health team comprising a senior occupational therapist, a senior social worker and an experienced clinical psychologist.

Institutional grants, awarded by the Discovery Foundation in 2022 and 2023, to the Departments of Psychiatry and Psychology respectively, have facilitated continued professional development. Mentorship and training enable district-level medical officers to complete postgraduate diplomas in mental health, with several progressing to specialist psychiatric training. Within the psychology department, emphasis has been placed on developing contextually appropriate clinical competencies, particularly in neuropsychological and neurodevelopmental assessment and various therapeutic modalities. Funding has also been used to provide equipment and training to the wider regional mental health teams.

Services to people living with disabilities

Given limited access to private care by patients, long waiting lists for services and barriers to care such as transport costs and time away from work, interventions must be highly targeted. Clinicians in this context practise very focused listening, building of rapport, accurate assessment and formulation skills and targeted interventions. It takes particular skill to work effectively.

Cerebral palsy

Across the two hospitals, a Cerebral Palsy Centre of Excellence has been established and psychologists participate in interdisciplinary teams supporting individuals with cerebral palsy and their families. This includes neurodevelopmental and cognitive assessments for intervention planning and school placement, along with psychological support of families.

Neurodevelopmental disorders

Supportive psychotherapy is offered for families of children with genetic syndromes. A dedicated weekly neurodevelopmental psychology clinic provides both diagnostic assessments and follow-up care. A WhatsApp-based support group for caregivers of children with autism spectrum disorder (ASD) offers accessible psychosocial support, supplemented by in-person sessions focusing on communication, toileting, eating and behavioural management. This is coordinated by the child psychiatric nurse and has input from various members of the multidisciplinary team.

Intellectual disability

Collaborative work with the Department of Education includes the assessment of children with intellectual disability to facilitate access to care dependency and appropriate schooling. Psychoeducation for caregivers and professionals regarding the *South African Sterilisation Act No 44 of 1998* (Republic of South Africa, 1998) and the rights of girls and women remains ongoing.

At the general hospital, a weekly clinic provides cognitive and functional assessment for social grants. A new partnership with a local school has enabled intellectually disabled students to access competitive swimming opportunities. Collaborative work with the Department of Justice includes a weekly forensic clinic, evaluating victims of sexual abuse and assessing criminal capacity in children, with many presenting with comorbid intellectual disability. Psychologists are called on by the courts to provide reports and expert evidence if required. There is an ongoing collaboration to provide psychoeducation to the prosecutors in the region regarding access to justice for people with intellectual disability.

Gender-based violence

Therapeutic services are provided through the Thuthuzela Care Centre for survivors of sexual and gender-based violence, aiming to prevent post-traumatic stress disorder and the resultant emotional disability.

Chronic illness and functional loss

Psychological assessments and support are provided to renal patients requiring decisions on levels of care. Inpatient referrals include individuals with recent amputation, spinal injuries or burns who require assistance adjusting to disability and functional change.

Mental illness

Both hospitals have clinics for new referrals and initial assessment. These services are often oversubscribed, with waiting periods exceeding 3 months. Psychologists work closely with psychiatry to provide therapeutic support for individuals with severe and persistent mental illness. An on-call psychologist is available daily for urgent referrals. Referrals to these clinics come from within the hospital, the district hospitals, the PHC clinics and non-governmental organisations (NGOs).

Hearing impairments

Recently, the team has expanded its capacity to assess individuals with significant to profound hearing loss requiring cochlear implants. Support and mentorship were received from audiology colleagues and experienced psychologists at Baragwanath Hospital, Gauteng.

Gender-affirming health care

An ongoing process of psychoeducation and service development seeks to address the healthcare needs of gender-diverse individuals who, because of disabling social, structural, and institutional barriers, experience limited access to gender-affirming care.

Outreach

Given the geographic dispersion of district hospitals without psychologists, an outreach programme was developed to support mental health colleagues in remote areas. Each general hospital psychologist is responsible for specific district hospitals, establishing referral pathways and offering direct clinical services. These services often focus on intellectual and neurodevelopmental disability assessments required for access to education or grants. Training workshops are provided for broader mental health teams and tailored to district-level requests. Outreach logistics include both car and air travel. Partnership with Red Cross Air Mercy Services has enabled access to hospitals that are otherwise 4 h – 5 h away by road. A detailed explanation of this model of collaborative care is due to be published in a local journal towards the end of 2025.

Ongoing initiatives

Training

Accreditation of clinical psychology internship placement has been applied for with the Health Professions Council of South Africa. Provision of clinical training opportunities for student psychologists from the University of Zululand is in process. Infrastructure limitations remain a significant barrier to providing local professional training.

Research

Active collaborations are underway with national and international research institutions and staff are engaged in postgraduate qualifications or ongoing research. Current interests include:

- integration of mental health services at PHC level
- development of mental health screening tools for children and adolescents
- the integration of cultural understanding and practices in mental health care
- gender-affirming health care
- pain and palliative care
- parenting practices
- autism spectrum disorder in this context
- neuropsychological and cognitive assessment in this context
- using the monthly statistics collected to describe the work of a rural psychologist.

Conclusion

The questions originally posed by Professor Swartz remain highly pertinent, with answers continuing to evolve over time. Central among these are: What is the role of the clinical psychologist within a rural South African context? How can disability be effectively foregrounded, and how might its prevalence and associated needs be accurately assessed and represented? Furthermore, how can we meaningfully engage and collaborate with persons with disabilities – across diverse forms and experiences – in the pursuit of improved mental health outcomes and the advocacy for equitable access to appropriate services?

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Data availability

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