Framing the debate on how to achieve equitable health care for persons with disabilities in South Africa

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This chapter attempts to frame the debate on how to achieve equitable healthcare coverage for people with disabilities in South Africa; this was done by reflecting on the needs and access gaps experienced, the drivers of inequity, and potential levers and solutions to resolving these issues.

People with disabilities in South Africa have greater healthcare needs than those without disabilities; they may require disability-related services, but on average they also experience poorer health. However, significant accessibility, informational, attitudinal, and/or financial barriers exist to accessing primary health care for people with disabilities. Additionally, a lack of disability-specific services, including rehabilitation, prevents many people with disabilities from accessing the services and assistive devices that they need. As a consequence, people with disabilities in South Africa have higher levels of unmet health needs and worse morbidity and mortality outcomes than those without disabilities.

An increased focus on people with disabilities is needed urgently in South Africa if the country is to achieve Universal Health Coverage (UHC). Greater levels of political will, leadership and funding are required to implement the robust disability-inclusive policies and plans that exist in South Africa. Pockets of good practice can inspire our thinking on how to implement these strategies on the ground.

The chapter offers a series of recommendations to improve the inclusion of people with disabilities in UHC in South Africa. This may include developing institutional disability-inclusive policies, establishing insurance systems that cover disability needs, staff training and sensitisation around disability, developing standardised and easy-to-use disability audits for facilities and services, establishing patient databases and IT support structures, and developing service delivery models that utilise peer-supporters and educators. Improving the amount and quality of data through consistent monitoring and implementation research is crucial in order to understand and monitor the issues, and to understand what works in providing services to people with disabilities.

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Introduction

Universal Health Coverage (UHC) means that people can obtain all the health services they need, without incurring financial hardship.1 Equity is at the heart of UHC, and is based on the commitment that these healthcare services be effective, accessible and of acceptable quality for all population groups and across the continuum of care. Achievement of UHC is a key ambition of the global health community and the Sustainable Development Goals (SDGs).2 Recent decades have witnessed progress towards UHC, including in South Africa.3 However, it is increasingly clear that some groups need additional attention in order for UHC to be achieved, and the one billion people with disabilities globally constitute one such group.4

Global data show that on average, people with disabilities have a greater need for healthcare services than people without disabilities, yet they face a range of barriers to health care, and therefore often have worse access.4,5 This inequity in healthcare access for people with disabilities, who make up 15% of the world’s population, may threaten the achievement of UHC.5 The importance of focusing on disability in relation to UHC is increasingly recognised. The 2019 Declaration on UHC, following the United Nations (UN) High-level Meeting (23 September 2019), includes the requirement to “Increase access to health services for all persons with disabilities, remove physical, attitudinal, social, structural and financial barriers, provide quality standard of care and scale up efforts for their empowerment and inclusion, noting that persons with disabilities ... continue to experience unmet health needs”.5 The right to healthcare access is also recognised in the UN Convention on the Rights of Persons with Disabilities (UN CRPD).7

The healthcare experiences and needs of people with disabilities vary widely between settings, thus in-depth consideration needs to be given to the situation in different countries. This chapter attempts to frame the debate on how to achieve equitable healthcare coverage for people with disabilities in South Africa; this was done by reflecting on the needs and access gaps experienced, the drivers of inequity, and potential levers and solutions to resolving these issues.

Healthcare status and needs of people with disabilities

The 2016 South African Community Survey and 2011 national Census show that approximately one in seven people in South Africa have at least some functional difficulties (16.1% Community Survey, 17.2% census), while around 4% experience severe functional difficulties (4.4%, 4.3%).8 Although sparse and patchy, the available evidence on health status of people with disabilities in South Africa9 shows that, on average, people with disabilities have worse health,9 a higher prevalence of chronic conditions,10 psychological conditions,11 diabetes12 and HIV,13 and higher mortality levels.14 There are a variety of reasons why people with disabilities experience worse health.5 By definition, people with disabilities have an underlying health condition and impairment (e.g. cerebral palsy and physical impairment),15 which are linked to other health needs (e.g. risk of urinary tract infections among wheelchair users). People with disabilities are also on average older, poorer and more marginalised,4 which are all known risk factor for poor health. They may also have more risk factors for poor health, such as experiencing violence,16 sedentary lifestyle, use of alcohol, tobacco and drugs,17 and high blood pressure and cholesterol.18 Yet, people with disabilities face barriers to healthcare services, as described below, which further threaten health.

People with disabilities will therefore, on average, have greater general healthcare needs than others in the population. They will also require regular healthcare services (e.g. vaccinations) and potentially specialised healthcare services, such as physiotherapy. Equal utilisation of healthcare services will therefore not allow people with disabilities to achieve the same health outcomes as others in the population, given their greater needs. Health equity will only be achieved through additional focus on service provision for people with disabilities.

Healthcare barriers facing people with disabilities

People with disabilities often face greater difficulties than others when seeking healthcare services, despite their greater overall need.5,9 Barriers include:

- **Inaccessibility of services and transport.** For example, a disability audit of primary health care (PHC) clinics in KwaZulu-Natal showed that only half of the facilities had essential features such as ramps, doors and toilets that provide wheelchair access, and almost none provided information in Braille or offered sign language interpretation.20
- **Unaffordability of services.** People with disabilities bear additional costs related to disability, e.g. specialist transport costs, and additional care and support, yet they are on average poorer.5,9 Disability grants may contribute towards these costs, but are often insufficient.21
- **Negative attitudes and discrimination.** Healthcare staff may have negative attitudes and discriminate on the grounds of disability.18,22 Healthcare workers often lack the skills and training to accommodate the needs of people with disabilities as medical training remains
focused on impairment-related needs.\textsuperscript{19,22} Worse still, there are reports of mistreatment by healthcare workers, for instance mistreatment of women with hearing impairment attending pregnancy and maternity services in Cape Town.\textsuperscript{23} Such challenges may be compounded in this country as healthcare providers often have an excessive workload and lack resources and training to provide care for people with disabilities.\textsuperscript{24} On the ground, this translates not only into negative attitudes but also to lack of confidence on the part of healthcare staff.\textsuperscript{25} In a pilot study done in KwaZulu-Natal, healthcare workers revealed that they did not know that a person with disabilities can be infected with HIV, and reported lacking the required skills to communicate effectively with people with disabilities.\textsuperscript{26}

- Lack of access to information on health and health services.\textsuperscript{27} For instance, people with disabilities in South Africa have been shown to lack knowledge of treatment options and suitable assistive devices, and as a consequence, they tend not to seek services.\textsuperscript{26} Knowledge about impairments may be low as screening and diagnosis are not routinely integrated into PHC.\textsuperscript{27} Information barriers are particularly difficult for people with certain impairment types, such as hearing loss,\textsuperscript{28} as there is often a lack of interpretation services.\textsuperscript{23}

- Widespread gaps in the availability of disability-specific care. South Africa has 7 937 registered physiotherapists, or 137 per million population, less than half the number in countries like the USA and Australia.\textsuperscript{29} Other generalist rehabilitation services are also not widely available in South Africa, such as speech and language therapy,\textsuperscript{30} occupational therapy,\textsuperscript{31} ear and hearing services,\textsuperscript{30} ophthalmology,\textsuperscript{32} and psychiatry.\textsuperscript{33} These services are not only scarce, particularly outside the private sector, but they are also inequitably distributed, with rural areas being the most deprived.\textsuperscript{34}

Not all people with disabilities will experience barriers in the same way. Inequities in access to healthcare services may be particularly great for people with disabilities who live in rural areas, those who are older, and those who have more severe or less visible impairments.\textsuperscript{19,35} Gender differences are relevant as women often report more barriers than men,\textsuperscript{35} particularly for sexual and reproductive health (SRH) services.\textsuperscript{36} There are also facilitating factors in accessing healthcare services, such as good social support\textsuperscript{25} and higher education levels.\textsuperscript{37}

Failure to achieve UHC for people with disabilities

Barriers to service will likely lead to significant unmet healthcare needs for people with disabilities,\textsuperscript{9} although data related to this issue are extremely sparse in South Africa. Barriers may also translate into poorer-quality services for people with disabilities when they do seek health care. People with disabilities are less likely to have health insurance,\textsuperscript{32} and are vulnerable to catastrophic health expenditure when seeking health care in South Africa.\textsuperscript{21} Together, this emerging evidence shows that people with disabilities in South Africa experience challenges across key aspects of UHC: access to care, access to all services needed, and affordability and quality of services provided.

Failure to include people with disabilities in the journey towards UHC in South Africa can be illustrated using the example of HIV. Local data show that people with disabilities exhibit more risk factors for HIV infection than people without disabilities; for example they were found to have less knowledge about HIV, to practise inconsistent condom use more often, and to have more than one sexual partner or engage in casual or transactional sex more frequently.\textsuperscript{13,37} Additionally, young people with disabilities lack access to HIV information and comprehensive sex education,\textsuperscript{38,39} and experience difficulties in accessing HIV testing and treatment services.\textsuperscript{40} Consequently, the data suggest that HIV prevalence might be higher among people with disabilities, in addition to the fact that living with HIV can lead to disabilities.\textsuperscript{13,37} Developing disabilities may also be associated with lower adherence to antiretroviral therapy (ART), yet rehabilitation is not integrated into HIV care.\textsuperscript{42} The continued lack of focus on disability will, therefore, make it more difficult to reach national and international HIV targets for testing, treatment, and viral suppression.

Disability and UHC in South Africa – why do inequities persist?

Vulnerability to poor health among people with disabilities and their barriers to healthcare access in South Africa have been known for some time, so why are these inequities persisting?\textsuperscript{9} These inequities result from the underlying drivers of poor healthcare service access, including inadequate legislation and policy, insufficient funding, poor leadership and management, and/or lack of data and evidence.\textsuperscript{5} The relevance of these issues in South Africa will be considered, in turn.

South Africa is known for its progressive health and social policies that aim to achieve UHC and address the inequalities of the past.\textsuperscript{14-41} The country is currently undertaking major health system and finance reforms. It is developing a National Health Insurance (NHI) scheme, set out in the 2019 National Health Insurance Bill, which will provide health cover for all South African citizens and permanent residents.\textsuperscript{45,46} The NHI scheme aims to contribute to the achievement of UHC through creating a funding mechanism to provide “access to quality healthcare services that are delivered equitably, affordably, efficiently, effectively and appropriately”.

Framing the debate on how to achieve equitable health care for persons with disabilities in South Africa
The policy and bill outlining the NHI scheme prioritise vulnerable groups, and lay out three fundamental elements relevant to people with disabilities. First, the policy promises activities for “infrastructure improvement”, potentially including accessibility of services. Second, it highlights that disability and rehabilitation services will be “fully integrated into primary healthcare (PHC) with a view to increasing care, treatment and rehabilitation”, including provision of assistive devices and prostheses. Third, the policy and bill commit to prioritising people with disabilities, including their ability to access services close to where they live, potentially through the provision of mobile services.

Additionally, national strategies in priority programmes address the increased vulnerability of people with disabilities. These include the National Strategic Plan (NSP) on STIs, HIV and TB (NSP 2017-2022) and the Framework and Strategy for Disability and Rehabilitation Services (FSDRS). The NSP 2017-2020, rated one of the most inclusive NSPs in the region, goes as far as to identify specific programmes, such as training of healthcare workers, peer support mechanisms and rehabilitation to reach persons with disabilities. South Africa has, therefore, stated its intention to improve the inclusion of people with disabilities in the health system through its legislation and policy. Collectively, these commitments are in line with the obligations set out in the UN CRPD, which was signed and ratified in South Africa in 2007.

Yet, people with disabilities in South Africa continue to experience inequitable health care, even though appropriate policy, legislation and strategic plans are in place. Health policies state the intention to deliver services, and strategies provide more information on the ‘how to’, but they need to be operationalised and translated into budget items in order to be implemented. Budget allocation for inclusive policies and strategies is often overlooked and therefore the disability components of health policies and strategic plans have been poorly implemented, if at all. For example, despite the NSP 2017-2022 identifying the need to provide healthcare workers with training on disability, this recommendation has not been operationalised, hence at mid-term review, healthcare workers still had not received disability-sensitisation training and many lack the understanding and skills to provide SRH services to people with disabilities.

There are, of course, competing demands on limited healthcare budgets in South Africa, which could explain the lack of focus on disability. Disability may be seen as something to fund once pressing issues like COVID and HIV are under control. There also appears to be a lack of co-ordinated leadership and resources for dedicated people in the National Department of Health (NDoH) responsible for disability. Poor planning on how to implement disability inclusion, ranging from the NDoH to local facility level, is another concern. For instance, a recent Health Systems Trust report highlighted that disability and rehabilitation programmes are often excluded in the workplans of health facilities, and are not well integrated at health facility and local community level.

The persistent health inequity experienced by people with disabilities can therefore be attributed to gaps across the building blocks of the health system, including health workforce availability and skills, financing, leadership and governance, but perhaps most fundamentally, lack of relevant data to inform planning. International targets on health, such as SDG3 and UHC, lack indicators around disability, in contrast to other SDGs (e.g. education and employment). Similarly, the new framework for measuring UHC proposed 23 indicators, none of which referred to rehabilitation or were disability-specific. Data on health inequities with regard to disability are rarely collected in South Africa, in contrast to health inequities in gender and ethnicity. As an example, the 2019 Statistics South Africa report on Inequality Trends in South Africa, used national data to compare health metrics for people from different groups (e.g. race, those with or without medical aid, chronic conditions), resulting in a range of recommended improvements. However, this 234-page report ignored disability. Within healthcare systems, disability is often not recorded or inconsistently recorded in medical records, making disaggregation of data by disability impossible (e.g. for COVID incidence and mortality). There is also little known about the effectiveness of reaching people with disabilities with different types of health services as both evaluation research and routine monitoring and evaluation are scarce. It is not possible to plan, budget, monitor or enforce activities for disability inclusion without the relevant data.

Better data are required on the healthcare needs and access of people with disabilities, although access is complex to measure. In assessing equity, one cannot directly compare utilisation of healthcare services alone by disability status, as on average, people with disabilities have higher healthcare needs. Instead, coverage is a more relevant measure, meaning whether people obtain the services that they require, including general health care (e.g. the proportion of people with HIV on ART, stratified by disability) and specialist care (e.g. the proportion of people in need or receiving physio-, speech or occupational therapy). Data are also needed on affordability and quality of services for people with disabilities. These measures can be collected through disability-specific population-based surveys or by including measures of disability in general health surveys. Inclusion of disability indicators in healthcare records can also help to disaggregate data by disability, and uncover patterns and vulnerabilities (e.g. incidence and mortality from COVID among people with disabilities). Indicators relevant to disability should be included in routine monitoring implemented by the NDoH, such as the number and distribution of rehabilitation professionals or the proportion of healthcare facilities that are accessible.
Learning from good practice in South Africa

Interventions to improve healthcare coverage for people with disabilities are needed once the relevant barriers and issues have been revealed through better data collection. South Africa already has innovative practical examples of how to drive equity in healthcare for people with disabilities.

Interventions can aim to improve individual access, such as by using SMS messages to make information more accessible to deaf people. There are also examples of access issues tackled at facility level. For instance, a simplified disability audit for SRH services has been developed, which assesses access among people with diverse impairments and whether facilities are linked to disability, rehabilitation and social services. This tool can be used by lay healthcare workers and people with disabilities themselves, and therefore inspires community participation and awareness-raising around gaps in access.

However, the barriers to healthcare access are diverse and interconnected, and thus more holistic interventions may be needed. One such initiative is the Manguzi wheelchair seating programme from a rural area in KwaZulu-Natal. It illustrates how to increase access to appropriate wheelchairs and mobility training, while overcoming diverse barriers. The key to success is the local rehabilitation team, which forms part of the multidisciplinary hospital service. This team has developed disability training for hospital staff to sensitise them to the importance of appropriate and timely wheelchair seating, physical access and mobility training, and attitudinal barriers. Structural barriers were addressed by developing an institutional wheelchair policy with the hospital that ensures seating of all eligible patients on the day of assessment (e.g. instituting a purchasing plan for wheelchairs and supplies), and training staff to repair or reuse equipment and to adjust interim wheelchairs. A ‘portable service’ was developed to overcome geographical and financial barriers; this involves visiting PHC clinics twice a month with wheelchair outreach clinics. Social support needs for their clients are also tracked. Mobility training is offered during the outreach visits via trained peer-supporters (i.e. other wheelchair users). The choice of peers makes the programme logistically more feasible, but also empowers people with mobility limitations to be part of the solutions concerning them, and ensures that training is locally appropriate.

One of the important enablers of this initiative is the committed local team, which ensures that local planning and implementation considers staff and resource allocations, capacity building, inclusion of people with disabilities and effective monitoring, tracking and evaluation.

Another good-practice example is the Workability model, which illustrates how information technology can be utilised to increase effectiveness of services and systematic change. Workability provides rehabilitative care to workers covered under the Compensation of Occupational Disease insurance system. Workability uses a comprehensive care model including health and social components. It developed an IT support and data management system, which enables the organisation to drive inter-disciplinary collaboration, targeted patient information and education, communication between different stakeholders (e.g. client, employer, therapist), personalised and cost-effective patient therapy plans, and assessment of efficiency, costs and outcomes. The system is dependent on access to data, computers, internet connectivity and staff who are computer literate. The extra insurance system is crucial to this model as a funding source, but the technology is also important to inspire service delivery under NHI.

These good-practice examples provide ideas on how service delivery can be improved for people with disabilities. Key lessons are that the interventions should address existing barriers and be developed with or by people with disabilities and dedicated staff on the ground in order to be effective and acceptable. Solutions should be data-driven, and recognise the different needs of people with disabilities. Importantly, they should be adequately resourced, in terms of both staff and budget, to ensure access. However, these examples are likely to remain patchy and sparse without a national, NDoH-led imperative that is monitored, enforced and budgeted, confirming that health services must be inclusive of people with disabilities.

Conclusions

In South Africa, people with disabilities experience greater healthcare needs than others, but they also face substantial barriers in accessing services and lack of availability of disability-specific services. These health system gaps arise from lack of political will, leadership and funding to implement the robust disability-inclusive policies and plans that are in place. Lack of data is also a major impediment, as data are needed to identify what the issues are and which solutions should be implemented. An increased focus on people with disabilities is needed urgently if South Africa is to achieve UHC.

Recommendations

- Commitments made in the policy and legal framework supporting the inclusion of people with disabilities in UHC must be monitored and enforced by the NDoH, in collaboration with people with disabilities. Strong leadership is needed to guide implementation of existing strategies through ensuring allocation of funding and resources to disability and rehabilitation services within the NDoH and among collaborators (e.g. the South African National AIDS Council).
• The disability grants and the NHI scheme (once it is operational) will help to meet the healthcare costs for people with disabilities in South Africa. However, the above funds must be sufficient to cover the costs of all required services, as well as transport costs.
• More and better data are needed on the health status, healthcare coverage and affordability and quality of healthcare of people with disabilities in South Africa. These data can be generated by conducting targeted surveys, and by including disability measures in routine data collection and funding of disability-specific research.
• People with disabilities must be empowered to access healthcare services through provision of accessible healthcare information, in different formats. They must be central to all decision-making on their health, including at national and policy level.
• Provision of rehabilitation, assistive devices, and other specialist services must be scaled up for people with disabilities through dedicated budgeting; plans must be implemented and monitored across levels, from the NDoH to facility level; and consideration must be given to task-shifting of responsibilities to mid-level cadre healthcare professionals.
• All cadres of healthcare workers must be trained to understand the complexity and diversity of disability, respond more effectively to the needs of people with disabilities, and overcome attitudinal barriers.
• Health facilities must meet minimum accessibility and inclusion standards, which need to be developed and agreed on. They should utilise patient information databases to direct services where they are needed and work with peers to deliver services in an appropriate and acceptable way.

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References


