



# Disability and rehabilitation: Essential considerations for equitable, accessible and poverty-reducing health care in South Africa

## Authors:

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**T**he right to health for people with disabilities in South Africa is supported by both the South African Constitution and the country's ratification of the UN Convention on the Rights of Persons with Disabilities. However, to date, health service planning and provision have tended to overlook rehabilitation as a component of primary health care. Evidence suggests that people with disabilities and their families experience greater health risks, but systematically worse access to care than their non-disabled peers, especially with regard to South Africa's quadruple burden of disease. Access barriers include environmental, transport and cost challenges, but also serious system limitations, including programme design, lack of health worker knowledge and skills in working with disability, and the widespread absence of planning and resourcing for rehabilitation.

As the experience of disability intersects with priority health conditions such as HIV and AIDS, and non-communicable diseases, there is reason to believe that the effectiveness of other programmes may be curtailed, unless disability is considered in health system design. Disability is also strongly related to other vulnerabilities, including gender, race, age and rural location. Disability and poverty tend to be mutually reinforcing, both because poor people are at greater risk of becoming disabled, and because people with disabilities are more likely to become or remain poor.

Primary health care re-engineering offers a vehicle for making health care more accessible to people with disabilities, preventing disability through early intervention, and making rehabilitation services available and accessible to all. Health systems strengthening should now look to the universal design of facilities and activities, the incorporation of disability considerations into all health programmes, and the resourcing of rehabilitation services, particularly at primary health care level, as a matter of urgency.

Primary health care  
re-engineering is a vehicle  
for making health and  
rehabilitation services  
accessible to all.

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## Introduction

Health is the basis for every citizen's participation in society, and thus for access to all other socio-economic rights, including the rights to education, decent work, and full cultural and social participation.<sup>1</sup> The right to health has been fully recognised in South Africa's health policy and legislation since 1994,<sup>2</sup> yet much work remains to be done in building a health system that ensures this right for all South Africans without discrimination.

Equity in access to healthcare, rather than equality, forms the basis for fulfilling the human right to health.<sup>3</sup> The need for specific accommodations for vulnerable populations is inherent in this understanding, and while attempts to achieve equity in access to health care have been made for some groups in South Africa (e.g. pregnant women and children under six years of age), significant inequities in access to health care remain. Geographical, racial and socio-economic variations in health service provision have been well documented,<sup>4</sup> but little attention has been given to disability as a population characteristic that cuts across, and in many cases compounds the negative effects of all of these factors.

The active role of the South African disability rights movement in the social and legislative changes of the early 1990s led to a number of highly progressive policies being adopted by the new democratic government, including some provisions influencing access to health care.<sup>5</sup> Unfortunately, much of this momentum has been lost in the intervening period, with many excellent intentions not being implemented as health services were otherwise transformed and expanded. However, the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) by South Africa in 2007 has lent a new urgency to the drive for full inclusion of people with disabilities. The UNCRPD, as the first legally binding international instrument on disability, includes "the right to the highest attainable standard of health without discrimination on the basis of disability" and requires its signatories to make the necessary accommodations in existing policies and services to realise these rights.<sup>6</sup>

In spite of this, health planners frequently overlook the needs of people with disabilities, or discount them as a minority group to be considered at some point in the future, once the pressing issues of HIV and child mortality have been resolved. This chapter seeks to demonstrate why disability must be considered now, as an integral part of health service planning and delivery, in order for these very targets to be achieved. A review of local and international literature will be considered in the light of local experiences and recent policy developments, leading to a set of recommendations by which the right to health for all may be realised within current health frameworks.

## Conceptualising disability

Disability is a complex construct, as any healthcare worker who has conducted an assessment for a disability grant will have realised. Indeed, in the public health service, this is the context in which the term 'disability' is most commonly encountered, and the grant is frequently the main intervention offered to people whose health condition or impairment can no longer be remediated with curative care. While the grant is undoubtedly beneficial in compensating for the additional costs and lost productive capacity related to

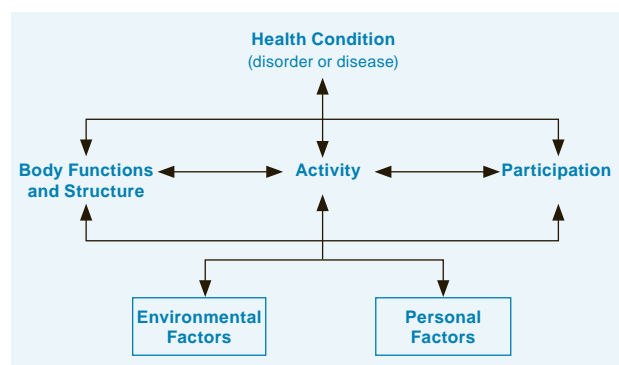
impairment,<sup>7</sup> it has not helped to change the prevailing thinking within the health system that relegates people with disabilities to being 'cared for', rather than supported (and expected) to play full and active roles in society.

The international disability movement, including South Africa's, has long fought both such a 'welfarist' approach and the medicalisation of disability as something to be fixed or cured within the individual. Instead, people with disabilities have propounded the understanding that disability resides as much in the attitudes, beliefs and overall structuring of society (including the built environment and the design of services), as it does in any physical, sensory or mental impairment. From this perspective, disability is an issue of human rights and development, and should be addressed in the restructuring of society, rather than in the 'fixing' of a person.<sup>8,9</sup>

The health system has a particular role to play in the prevention of disability, the equitable provision of health services to people with disabilities, and the provision of health rehabilitation.

In 2001, the World Health Organization moved away from an individual- and impairment-focused approach to describing disability (represented in the International Classification of Impairment, Disability and Health<sup>10</sup> by developing the International Classification of Functioning, Disability and Health (ICF)).<sup>11</sup> This represented a major step in bringing together the social and structural concerns of the disability movement, with the recognition of the impact of health conditions on people's participation in their communities. By conceptualising disability as arising from the interactions between a health condition and environmental and personal factors (see Figure 1), the ICF has brought about a shift in much health sector thinking, from considering individual pathology in isolation towards a broader understanding of health and function in context.

Figure 1: The ICF model of disability



Source: WHO, 2001.<sup>11</sup>

Significantly, the ICF presents disability as a universal aspect of the health/illness experience, which may affect the majority of people during their lifetime, whether on a temporary, permanent or episodic basis. This broadening of the definition of disability beyond long-term impairments positions disability as a cross-cutting issue with potential relevance to every aspect of health care.

The ICF's conceptualisation of disability as complex and multi-faceted makes it clear that people with disabilities are an extremely diverse group. A wide range of impairments in body structures



and functions, as well as a broad spectrum of functioning which depends on both environmental and personal factors, is covered in the ICF framework. The experience of disability is shown to intersect with demographic characteristics such as age, gender, urban or rural location, and socio-economic status, often reinforcing other vulnerabilities.<sup>12</sup> As such, an elderly woman heading a poor rural household who suffers a stroke will have a different experience of disability to a middle-aged urban man working in a large Information Technology company with the same condition. Both may have difficulty walking, using their affected hands, communicating and doing things for themselves, but the impact on their lives will be widely different. Their access to services will also be widely different.

## Disability prevalence in South Africa

Given its complexity, disability is not easily measured, and there is an acknowledged dearth of data on its prevalence, including in South Africa. While disability has been an indicator component in National Census and General Household Survey data since 1996, the use of differing disability definitions and screening tools has made it difficult to compare information across sources.<sup>13</sup> Even with more recent standardisation of disability screening methods in the General Household Survey and Census, technical and methodological issues can render comparison across regions and populations difficult. Self-reporting by household is subject to widely differing perceptions of whether a particular health experience constitutes a disability, while identification by impairment alone fails to account for the environmental and personal factors that translate a health condition into an experience of disability. Sampling strategies may exclude sections of the population that experience disproportionate levels of disability, for example, people living on the street or in institutions.<sup>14</sup>

The Census 2011 Profile of Persons with Disabilities in South Africa<sup>15</sup> calculated a national prevalence of 7.5% for those living with moderate to severe disability; however, this figure excluded children under five years of age, and people with psychosocial and some neurological conditions. By contrast, the World Report on Disability,<sup>16</sup> using figures from the World Health Survey 2002–4, attributed a 24.2% disability prevalence to South Africa (in comparison with an approximate 15% worldwide prevalence). These figures highlight how different methodologies may yield very different estimates, and there remains an urgent need for more accurate data, not only for overall disability prevalence, but also for disability among specific population groups and health conditions.

Burden of disease studies shed light on trends in population health which may be expected to have a bearing on disability prevalence. In South Africa, the quadruple burden of disease<sup>17</sup> has particular implications for the risks and types of impairments encountered (see Table 1). As mortality is reduced, more people are likely to be living with residual impairments. The availability of antiretroviral treatment for people living with HIV has had a particular impact in this regard, as people now live far longer with a disease that causes impairments in itself, as well as through side-effects of medication.<sup>18</sup> While international research has demonstrated this for some time, there are insufficient data on disability prevalence and experience among people living with HIV in South Africa.<sup>19</sup> However, a number of small-scale studies indicate a high rate of activity limitations and participation restrictions among this group.<sup>20–22</sup>

Table 1: The quadruple burden of disease and associated impairments

Disease burden	Examples of associated impairments
Maternal and child health	Birth trauma, cerebral palsy, stunting, developmental delay, mental illness, visual and hearing impairment
HIV and TB	Neurological impairments, dementia, mental illness, TB of the spine, joint disease, pain and fatigue, antiretroviral side-effects, ototoxic side-effects of TB medication
Trauma and violence	Spinal cord injury, traumatic brain injury, amputation, orthopaedic complications, mental illness
Non-communicable diseases	Stroke, diabetic retinopathy, neuropathies, amputation, mental illness, visual loss

Mental illness is another major source of disability, and is on the increase both in South Africa and worldwide. Recent local research indicates a 12-month prevalence of 16.5% for neuropsychiatric disorders,<sup>23</sup> which also ranks as the third leading cause of disability and death in the country, after HIV and infectious diseases such as tuberculosis (TB).<sup>24</sup> As reflected in Table 1, mental illness is often co-morbid with physical health conditions, again with strong links to the quadruple burden of disease.

## Disability and the health system

### Health risks of people with disabilities

While it is important to recognise that being disabled does not necessarily mean that one is ill,<sup>9</sup> people with disabilities have the same healthcare needs as the general population, and are often at greater risk of becoming ill. Research in southern Africa suggests an equal or increased risk of contracting HIV among people with disabilities, but also widespread exclusion of this group from prevention, treatment and support programmes, as well as from much HIV research.<sup>25</sup> People with certain mental health conditions are more likely to have physical illnesses such as hypertension and diabetes, while earlier occurrence of age-related conditions such as dementia have also been noted among some people with disabilities.<sup>26</sup> A recent study using data from the National Income Dynamics Survey (NiDS) demonstrated lower self-reported health status among people with disabilities, compared to their peers, with the lowest levels occurring among older adults and rural dwellers. People with disabilities were also disproportionately likely to have had TB, as well as certain non-communicable diseases such as stroke, asthma and heart problems.<sup>27</sup>

Poverty has been widely understood to have a strong relationship with the prevalence of disability, both because people with disabilities are at greater risk of being poor, and because poor people are at increased risk of disability.<sup>28,29</sup> The lack of appropriate data has made it difficult to quantify the relationship at scale in developing countries, including in South Africa.<sup>19,30,31</sup> Specific health conditions have been more definitively linked to poverty in large-scale international research, including mental illness,<sup>32</sup> and non-communicable diseases such as diabetes and cardiac problems.<sup>33</sup>

At a community and household level, the dynamics through which poverty and disability reinforce one another have been shown to be complex, interacting with multiple environmental and personal factors.<sup>34–36</sup>

There is some evidence to indicate that disability grants may improve the financial status of South African households; however, in other dimensions of deprivation, including access to services, education and employment, people with disabilities remain disadvantaged.<sup>7,37</sup> Where community income levels are low, grants will be used to meet basic household needs, rather than compensate for disability-related costs.<sup>38</sup> Where services are not designed to accommodate people with disabilities, cash transfers in themselves are insufficient to overcome barriers to health services, education and others.

Where poverty and disability intersect, people with disabilities will be exposed to multiple health risks. Even within other disadvantaged groups (e.g. rural communities), they may be systematically disadvantaged relative to their non-disabled peers. Children with disabilities are more likely to be malnourished,<sup>39</sup> and are more likely to suffer abuse and neglect.<sup>40</sup> People of all ages with disabilities have less access to water and sanitation.<sup>41</sup> International research indicates greater inequality between people with disabilities and their non-disabled peers in middle-income countries than in lower-income countries, indicating that as a country develops, people with disabilities may be excluded from development efforts.<sup>29</sup>

These risks affect not only persons with disabilities themselves, but also their households. The financial, physical, emotional and social burden of caring for a relative with a disability can have multiple impacts on family members, both increasing their risks of ill health, and reducing the likelihood that they will seek health care themselves.

## Access to healthcare

Access to healthcare for people with disabilities is a well-established concern, particularly in low- and middle-income countries (LMICs).<sup>42</sup> In South Africa, as in other settings, barriers include both structural factors (e.g. lack of accessible transport, inaccessible facilities and equipment), and healthcare process challenges, including long waiting times, negative attitudes and lack of knowledge among healthcare workers, and communication difficulties, particularly the lack of Sign Language interpreters.<sup>43</sup> These factors are compounded in rural districts, where travel times and costs may already be much higher, education and information poorer, and health services more scant and poorly resourced.<sup>43–45</sup>

According to Moodley and Ross, people with disabilities in South Africa are less likely to have medical insurance, and more likely to use public health facilities.<sup>27</sup> International evidence indicates that people with disabilities use health services more,<sup>16,46,47</sup> and also have higher rates of unmet healthcare needs. Although such data are scarce for South Africa, the 'treatment gap' for both mental health care and health rehabilitation in general has been described.<sup>23,48,49</sup>

Even in the presence of free primary health care and fee exemptions for people with disabilities, the financial cost of accessing health care is a major barrier for many.<sup>42</sup> A study on barriers to accessing health care for people with chronic conditions in Mpumalanga Province found that only 35% of participants were receiving regular treatment, with financial costs of health care sometimes reaching up to 60% of household income.<sup>50</sup> Another study at the same site found that only 58% of people eligible for fee exemptions received them, and for rural residents, transport accounted for almost half of the costs incurred.<sup>51</sup> Public transport for people with disabilities is systematically more expensive than for others, as they must generally

also pay for an accompanying relative, and wheelchairs are usually billed as an extra fare. Those who cannot use public transport typically have to pay exorbitant amounts for private car hire (hiring a neighbour's car in some areas can cost hundreds of Rands for a trip to the district hospital). In rural areas where public transport is scarce, the costs of access may be compounded by service issues such as poor drug supply, lack of appropriate referral and long waiting times, leading to wasted and repeat visits.

## Quality of care

Reaching the point of care is only one aspect of the access process. Less well understood is the quality of care experienced by people with disabilities and their families. McColl et al.,<sup>52</sup> in an investigation of primary care practices in Canada, found that doctors were less likely to conduct a physical examination of a patient with a disability. Reasons for this included a lack of skill and confidence in adapting clinical techniques, and inaccessible equipment (e.g. scales designed only for standing users), but the most significant factor seemed to be the additional time required to assess and treat such patients. Not only were their needs frequently multiple and complex, but communication was often more challenging and time-consuming, even where the appropriate supports (e.g. Sign Language interpreters) were available. This meant that people with disabilities often did not receive routine preventive care and screening, a pattern compounded by a lack of understanding among healthcare workers of the healthcare needs of people with disabilities.

Similar patterns can be observed in the pressured public health system in South Africa, where to date, many facilities remain inaccessible, staff shortages are high, and training in dealing with the needs of people with disabilities is infrequent. Healthcare worker attitudes towards people with disabilities have been widely cited as a barrier to healthcare access in South Africa,<sup>43</sup> although a better understanding of specific patterns of belief and attitude formation is required. Exclusion from specific programmes, particularly HIV care and sexual and reproductive health, has been documented.<sup>19,53,54</sup>

MacLachlan and colleagues suggest that the access to health care by people with disabilities is reflective of broader health system function, including intersectoral relationships, co-ordination of services, and societal factors such as transport and social support. By implication, general health service challenges (e.g. human resources shortages, drug supply) will have a disproportionate impact on people with disabilities and their households.<sup>55</sup> Further research in this area is urgently needed.

## Access to rehabilitation

In addition to general health services, people with disabilities also require specialist input in order to be able to realise optimum levels of health and functioning. Rehabilitation is included in the definition of comprehensive primary health care, alongside preventive, promotive, curative and palliative care,<sup>56</sup> but remains poorly understood by healthcare managers and workers in South Africa. Broadly defined in the UNCRPD as "a set of measures that enable people with disabilities to achieve and maintain optimal functioning within their environments",<sup>6</sup> rehabilitation in essence serves to translate regained or maintained health into healthy and productive life. While rehabilitation may include activities to prevent or remediate impairments in the person, its major contribution is

in addressing activity limitations and overcoming participation restrictions, through intervention in the environment as well as with the individual.

The World Health Organization's Guidelines on Community-based Rehabilitation describe the current gold standard for rehabilitation in both developed and developing countries.<sup>57</sup> Community-based rehabilitation (CBR) refers not only to services provided outside of institutions, but to a general philosophy which aims at the inclusion and full participation of people with disabilities in all aspects of community life. CBR shares core principles with comprehensive primary health care, including accessibility, affordability, acceptability, self-determination, empowerment and intersectoral collaboration. The CBR Guidelines cover education, livelihoods, social life and empowerment as well as health, and are based on the fundamental rights of people with disabilities in all of these areas.

While rehabilitation as a component of health care cannot possibly address the full range of these activities, health rehabilitation is an important precondition for access to all other rights. A child born with cerebral palsy may have a vastly different future, depending on whether or not she receives rehabilitation. Without it, she may struggle to communicate, eat, become mobile or do things for herself, and may develop secondary complications such as joint contractures and malnutrition. Her caregiver may be prevented from working in order to care for her, and the family may suffer financially, emotionally and socially, with multiple effects on their health. By contrast, a child who receives appropriate rehabilitation may be able to communicate, move around, be toilet-trained and become an active participant in her household and community. With the right support and environment, she may be able to attend school, enter the labour market, have her own family and live as a full member of society.

In South Africa, access to health rehabilitation, particularly in the public sector, is seriously constrained. Even in the relatively well-resourced Western Cape Province, research shows high rates of unmet need,<sup>49</sup> while only 26% of children with disabilities in a peri-urban township in Gauteng Province were found to be accessing rehabilitation services.<sup>58</sup> Assistive devices such as wheelchairs, crutches and hearing aids are widely unavailable, or subject to long waiting lists.<sup>58,59</sup> Problems cited by therapists across the country include inefficient procurement processes, lack of budget allocation, lack of transport to collect and deliver devices, and lack of spare parts and repair technicians. A lack of assistive devices may prevent people from attending school, accessing health care and seeking employment, yet they continue to be ignored in budget allocations and efforts to address other medical supply shortages.

Human resources for rehabilitation in the public sector are subject to the same challenges as other cadres of healthcare workers, including international migration, attrition, freezing of posts and migration to the private sector.<sup>a</sup> At present, no data exist on the extent of the shortage in South Africa, mainly because staffing norms for rehabilitation services have never been set, so that even existing figures on post vacancies cannot be said to represent the actual need. Internationally, the dire need for new human resource

strategies to meet the need for community-based rehabilitation is well documented.<sup>60</sup>

## Rehabilitation as a core component of primary health care

While rehabilitation is named as a core component of primary health care alongside preventive, promotive and curative care, in practice it incorporates aspects of all of these activities.

Prevention of health problems may be divided into primary, secondary and tertiary types, where primary prevention aims to prevent onset of a condition, secondary prevention aims to prevent advancement and complications, and tertiary prevention aims to enable a healthy life in the presence of the condition or impairment.<sup>16</sup> Figure 2 depicts these levels in relation to a 65-year-old man at risk of hypertension. The left-hand column shows the progression of the health condition (where preventive interventions fail), and the adjacent column matches each stage with the associated risks of further ill health. As can be seen, at each stage, the risks multiply and become more serious. The intervention column describes the type of preventive activity appropriate for the risks described. It will be noted that the primary and some secondary prevention activities form part of general primary health care (health education and antihypertensive drug treatment), but the bulk of secondary and tertiary prevention are person-specific activities carried out by a rehabilitation team. Furthermore, given the barriers for people with disabilities accessing even clinic services, it is clear that if primary prevention fails and no rehabilitation is available, further preventive and health-promoting services become progressively less accessible, resulting in a downward spiral of ill health and disability.

<sup>a</sup> Rehabilitation professionals include occupational therapists, speech and language therapists, audiologists, physiotherapists, orthotists and prosthetists, and the mid-level workers attached to these fields, as these are the cadres most commonly employed by the Department of Health to provide rehabilitation services. Other professions playing significant roles include psychologists, social workers, podiatrists, and orientation and mobility trainers, among others.

Figure 2: Levels of prevention for a 65-year-old man at risk for hypertension

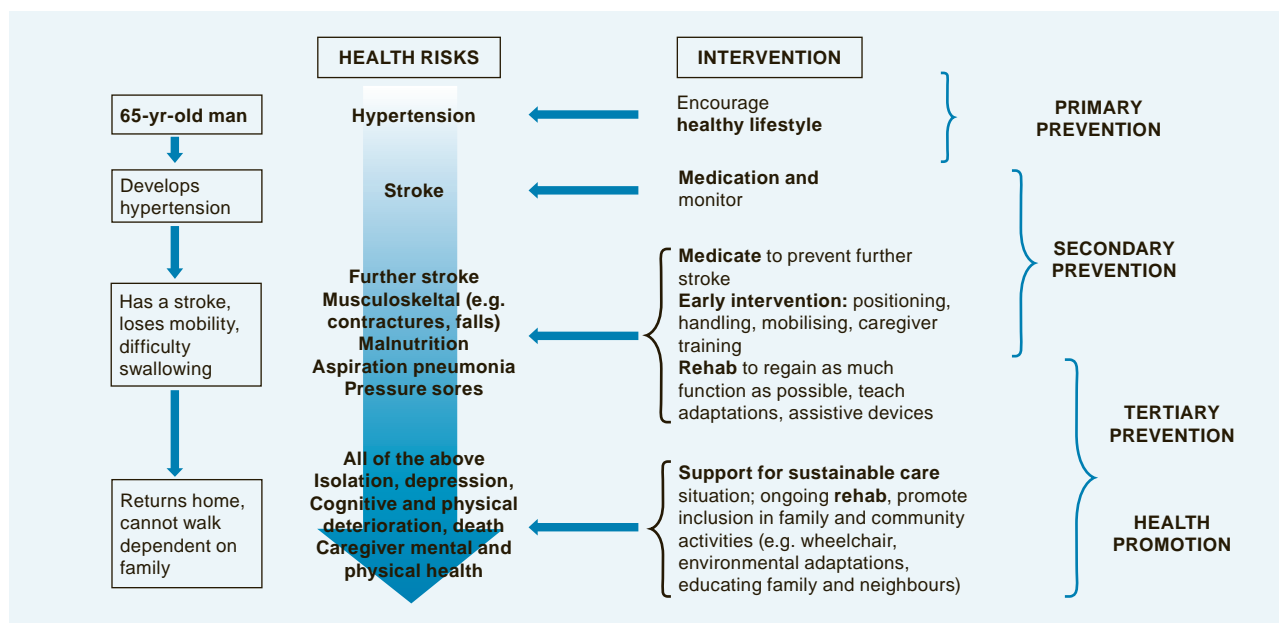


Figure 3 depicts the intersections of rehabilitation activities with other aspects of comprehensive primary health care. The range of health conditions for which rehabilitation may play a role is extremely broad, including musculoskeletal problems, mental health, neurological conditions, HIV and AIDS, developmental problems, communication difficulties, maternal and child health, and non-communicable diseases. As is evident, rehabilitation is a complex and person-specific process, extending beyond the acute stage of a health condition, and necessarily encompassing inpatient, outpatient (hospital or clinic-based) and community settings.

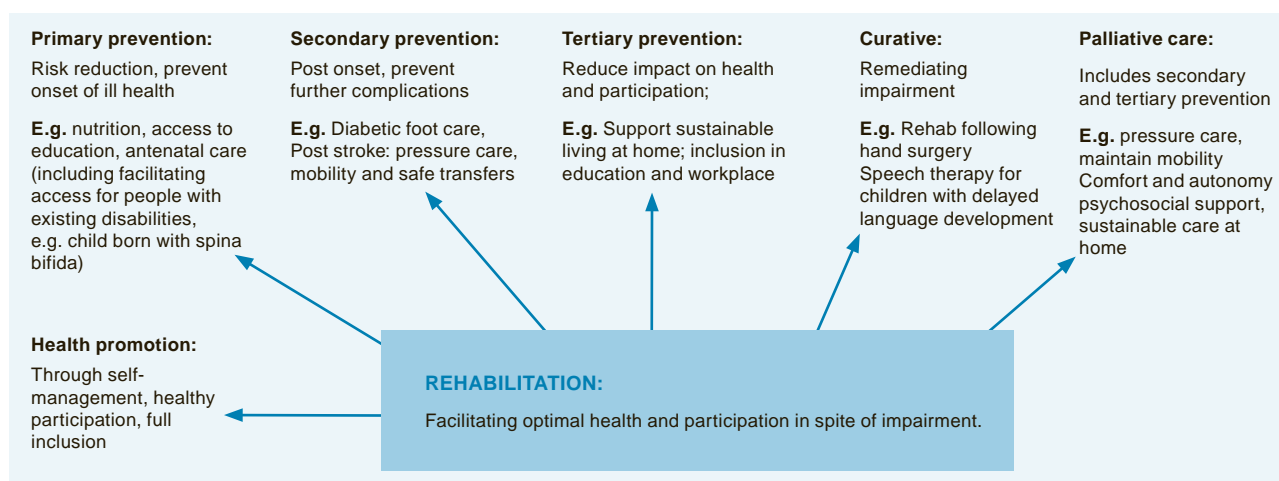
In spite of the obvious intersections between rehabilitation and other critical aspects of primary health care, primary health care re-engineering policy and planning to date have largely failed to include it. Primary Care 101, the guide for primary health care nurses treating adults at clinic level, almost entirely omits referral to rehabilitation in its protocols, even for obviously disabling conditions such as stroke and fibromyalgia. Physiotherapy is mentioned in relation to musculoskeletal conditions such as back and neck pain;

occupational therapy only under arthritis, and speech therapy and audiology not at all, even in the guidelines for ear conditions. Occupational therapists are also omitted from mental health sections of the guide, despite their designation as specialist mental health workers under the Mental Healthcare Act (17 of 2002). The Standard Treatment Guidelines for both Primary Care and Hospital Levels reflect similar omissions, not only in indicating the need for rehabilitation referrals, but also in prompting clinicians to assess for residual impairments, even in conditions where these are common and often significant.

Promisingly, screening for impairments in children has been included in both the Road to Health Chart (RTHC), and the activities of School Health Teams. Unfortunately, the RTHC is often poorly completed in practice, and neither initiative has led to progress in the provision of services for children identified as having difficulties.

Another promising development has been that of Ward-based Outreach Teams (WBOTs), and strengthening of the roles of

Figure 3: Rehabilitation and comprehensive primary health care



community health workers (CHWs). House-to-house visiting offers excellent opportunities to identify people with disabilities, who are often hard to reach, and to link them with the necessary services. Again however, disability concerns have been largely excluded from guidelines for practice, data collection and training curricula, despite occasional mention of “disability care and rehabilitation” under the roles of the CHW. This would seem to reflect a superficial grasp of rehabilitation itself on the part of policy-makers, along with low expectations of people with disabilities’ potential to contribute to society.

Within HIV programming, there is acknowledgment that people with existing disabilities are particularly vulnerable to infection, and the National Strategic Plan on HIV, STIs and TB (2012–2016) outlines the need for accessible prevention and treatment services. However, the plan still fails to address the disabling nature of the diseases and their treatment, including the impact that disability is likely to have on adherence and retention in care.<sup>53</sup> Whilst rehabilitation is briefly mentioned under Strategic Objective 3 (Sustaining Health and Wellness), the only disability-related interventions actually outlined and budgeted for are for the primary prevention of impairments through medical treatment.<sup>61</sup>

The National Mental Health Policy Framework and Strategic Plan (2013–2020)<sup>62</sup> has been a more positive development towards realising the right to health care, including rehabilitation, for people with disabilities. Based on principles similar to those of the CBR, it provides for the development of community-based support and services to enable people with mental health conditions to be fully included in society. It remains to be seen how this will be implemented at provincial and district level. To date, the link does not seem to have been made between this framework and other rehabilitation planning, despite the potential for dovetailing and resource-sharing. Occupational therapists are largely omitted from this plan, as are mid-level rehabilitation workers, despite the potential that both cadres offer to address physical and mental health needs together in a holistic manner, at primary care level.

Planning for comprehensive rehabilitation services has lagged far behind other aspects of the health service overhaul in recent years. Following civil society pressure for implementation of the UNCRPD, a task team was established in 2013 to develop a rehabilitation strategy based on Primary Healthcare Re-engineering (PHC-R). Comprising representatives from the disability sector, the rehabilitation professions and academia, the team made some progress towards identifying key challenges and proposing solutions, but was significantly under-resourced, and isolated from overarching developments in the National Department of Health. There was also no mandate to address the failure of the National Rehabilitation Policy of 2000, which, although welcomed at the time as a promising move towards realisation of disability rights, was largely unimplemented.<sup>63,64</sup> At the time of writing, Department officials had prepared a final rehabilitation strategy document for submission to the National Health Commission in July 2015. It is not clear as to whether or not this strategy took account of the task team’s recommendations.

## What can be done?

Swartz et al.<sup>42</sup> state that “[h]ealthcare can be neither universal nor equitable if it is less accessible to some sections of society than it is to others”. The right to health care and rehabilitation, available as close to one’s home as possible, is entrenched in South African law through ratification of the UNCRPD, and yet it is clear that this is far from being realised for a large proportion of citizens. This affects not only the 7.5 – 24% of the population who already live with a disability, but also the many more at risk of developing disability due to common health conditions and environmental factors, particularly those living in conditions of poverty, and where access to general healthcare services is poor.

The remainder of this chapter outlines key recommendations to address this human rights imperative.

### 1 Improving access to general healthcare

Provision of healthcare as close as possible to where people live is an important step in making health care both more affordable and more accessible. Chronic care is particularly vulnerable to failure where access costs are unsustainable over time, and these services should be prioritised for provision at community and clinic level.<sup>50</sup> Outreach services by doctors, nurse practitioners and rehabilitation professionals may go a long way towards secondary prevention of impairments by reducing the material, opportunity and temporal costs of healthcare access. Concerns for cost-effectiveness of such services should take account of improved treatment effectiveness, and savings from prevented complications.

The need for affordable and accessible transport cannot be overemphasised as a means of increasing equitable access to health services. Strategies may include dedicated transport services for people with disabilities (e.g. Dial-a-Ride), transport vouchers, and partnerships with local public transport providers. Such measures would be of significant value in reducing healthcare inequities and potentially catastrophic costs, particularly for rural communities.

Ward-based Outreach Teams can play a critical role in connecting people who are at risk of or living with disabilities with services, and providing community-level support. For this to be effective, all healthcare workers need to be trained in disability issues, including specific health needs and available services. Households with a disabled member should be flagged as vulnerable, and reported and monitored accordingly. These teams should include trained rehabilitation workers.

Healthcare workers at all levels need to take account of disability issues, including health needs and access barriers, in clinical decision-making. Routine preventive and health promotion activities should be specifically adapted to include people with disabilities, and screening for impairments should take place at every level of care, with appropriate referral. These considerations should be integrated into all treatment guidelines, as well as monitoring and evaluation activities. Complex and multiple service needs should be carefully co-ordinated to streamline access costs for families, and communication between providers should be strengthened (including from other sectors such as education and social development).

Finally, universal design of all health facilities and activities is needed to ensure equitable access for people of all abilities. This includes



not only grounds, buildings and amenities, but also information, public health campaigns and communication with service providers.

## 2 Rehabilitation as an essential component of primary health care

Rehabilitation must be made available as a core component of essential health care, and integrated into all programmes and planning at primary care level. This chapter has described how rehabilitation is inherently applicable across health conditions and various healthcare activities, and it can no longer be considered an 'add-on' or vertical service. While rehabilitation has an important place in all levels of care, services should be concentrated as close to where people live and work as possible, both for accessibility and to allow rehabilitation to address environmental and social barriers to participation, and not merely the person's impairments and activity limitations. This will be best realised by including appropriately trained mid-level rehabilitation workers in every WBOT, such that they can both support generalist healthcare workers to address disability issues, and carry out CBR activities.

Rehabilitation workers at all levels should function as part of the multidisciplinary team (MDT). Collaborative activities such as ward rounds, in-service training and outreach play an important role in improving care co-ordination, effective referral and overall quality of care.

Specific linkages should be developed with programmes such as HIV and AIDS, and TB, and non-communicable diseases, including impairment screening and referral, and MDT attention to treatment adherence and access issues. Mental health care planning should include the occupational therapist and mid-level rehabilitation worker, who are both well placed to carry out proposed activities such as support groups, community education, and inclusion in the workplace and in education. Occupational therapists may also contribute to mental health assessments and other statutory processes.

Human resources for rehabilitation require urgent attention, including data on current workforce profiles and measures to establish staffing norms. Workforce planning processes to date have addressed only existing service levels, failing to take account of the expansion needed to fulfill South Africa's commitment to the UNCRPD, and the redress of significant inequities in service provision. Multi-skilled mid-level workers have been widely used to deliver CBR in low-resource settings, and efforts to establish such a category of worker are already underway. It is critical that such workers be adequately trained to work independently within a CBR framework, but also that appropriate support and supervision from a multidisciplinary professional rehabilitation team be available.

Material resources, including equipment, adequate working space, information technology and communication facilities, must be budgeted for systematically and in accordance with service standards. Budgets for assistive devices should incorporate allocations for spares and maintenance requirements, and budgeting and procurement processes should be tailored to avoid current backlogs and inefficiencies. Broadening the understanding of rehabilitation, and building political will to address disability issues, is essential for these processes to take place.

Transport for rehabilitation workers is imperative if services are to be accessible and effective. Clinic-based outreach, as well as home, school, workplace and community visits, should be understood as the core of primary care rehabilitation, and appropriate vehicles should be made available.

Finally, the training of rehabilitation workers, at both under- and post-graduate levels, should equip these personnel to work at PHC level within a rights-based framework. Training institutions in South Africa have made strides in this direction, but strategies for professional support, supervision and continuing development would stimulate the attraction and retention of public sector staff, and improve the quality of service available.

## 3 Strengthening the voices of people with disabilities in healthcare policy-making, planning and service provision

At the heart of a CBR philosophy is the commitment to realising the full participation of people with disabilities as citizens. Capacity-building and organisational support is needed to expand the number and diversity of people with disabilities who engage actively with government, and public consultations, dissemination of information and other civic activities should be accessible to all. Public education on the rights of people with disabilities should be expanded alongside other rights education. People with disabilities and their families can also play important roles in rehabilitation itself, as peer supporters, advocates, advisors and trained rehabilitation workers.

These activities may fall within both government and civil society roles, and cut across multiple sectors, including education and social development. The UNCRPD remains a powerful tool for change, and can be used as a rallying point for diverse groups, from HIV activists to organisations for people with disabilities.

## 4 Building the evidence base on disability, health and rehabilitation

Although sufficient evidence exists to demonstrate the urgent need for accessible healthcare and rehabilitation for people with disabilities, more detailed local research is needed to inform, and build the case for interventions that address the treatment gap.

The current health status and healthcare utilisation of people with disabilities must be investigated in order to identify existing inequities and monitor progress. This can be done through disaggregation of routine data by disability status, as is already being done in projects such as the NiDS, and the National Census. Data collected by the Department of Health, if handled in this way, would enable quantification of the intersection of disability with priority health conditions such as HIV and TB, as well as with other vulnerable groups such as women, rural dwellers and people living in poverty. This would inform resource allocation and programme design to target inequalities and improve effectiveness.

Such data collection should be complemented by population research on non-users of healthcare and on unmet need. There is reason to believe, given access challenges, that people with disabilities and their families are disproportionately represented in the non-user group, and that the inadequacy or absence of key services such as rehabilitation may be perpetuated when health planners base decisions on utilisation rates alone.

Health systems research is needed to understand how people with disabilities currently interact with health services, and to map care pathways and access barriers. Studying examples of best practice will help to identify innovative strategies and critical success factors for strengthening health systems to meet the needs of people with disabilities.

Finally, research is needed that links specific interventions to priority health outcomes. For example, the presence of community-based support and rehabilitation for people with mental illness should be tracked against relapse and re-admission rates. Retention in HIV care and adherence to treatment could be compared across services where rehabilitation is integrated into MDT care, and those where it is not. Cost-effectiveness calculations based on such research could help to leverage funding and creation of posts for CBR.

## Conclusion

This chapter began by introducing the right to health of all people with disabilities in South Africa, entrenched in our Constitution and further elaborated in the UNCPRD. The literature demonstrates that this group is not only sizeable, but also representative of some of our most vulnerable citizens, including many living with priority health conditions such as HIV and AIDS. Disability has long been ignored by policy-makers and planners, and this is not only short-sighted in terms of realising health goals, but also places South Africa in breach of its legal commitment to its own citizens, and to the international community. Recommendations have been made here for strengthening the health system to respond to the needs of all, including the integration of skilled and appropriate rehabilitation into the primary health care package. Without such changes, existing health inequities will continue to deepen, and “a long and healthy life for all South Africans” will remain beyond reach.

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