

Reimagining rehabilitation outcomes in South Africa

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Planning, monitoring and evaluation of service delivery for persons with disabilities must be designed to focus on long-term, holistic well-being and not merely 'impairment management'.

Health and rehabilitation outcomes are not only affected by health care or access to services but by a set of complex and multifarious factors linked to the social determinants of health. These include a range of social, political, economic, environmental, and cultural factors. Additionally, economic variability or instability impacts on the ability of persons with disabilities to achieve better health and rehabilitative outcomes, which in turn impacts negatively on their ability to enter or re-enter education and, ultimately, to transition into livelihood development.

This chapter argues that the accountability frameworks governing the provision of rehabilitation and development services designed to increase disability inclusion require critical re-thinking in order to meet the complex needs of persons with disabilities. The chapter discusses the ways in which rehabilitation and development programmes shape societal attitudes towards persons with disabilities and entrench beliefs about their capabilities, value and status,

and concludes that planning, monitoring and evaluation of service delivery for persons with disabilities must be designed to focus on long-term, holistic well-being and not merely 'impairment management'.

Three recommendations are made for the reimagining of rehabilitation outcomes: recognising and including persons with disabilities as key stakeholders in the rehabilitation process; critically evaluating the curriculum for the training of new rehabilitation workers; and contextualising the design and implementation of rehabilitation services by shifting from a resource-centred to a person-centred approach.

While designing indicators that measure both tangible and intangible outcomes is certainly challenging, this is essential if rehabilitation interventions are to facilitate the development of holistic well-being and greater socio-economic inclusion of persons with disabilities.

Introduction

Article 26 of the United Nations Convention on the Rights of Persons with Disabilities^a (UN CRPD) identifies the central role of rehabilitation programmes and services in promoting and facilitating the inclusion of persons with disabilities in education, health and employment, as well as their participation in all spheres of social life.¹ The Convention defines rehabilitation in broad terms, recognising a complex network of multi-disciplinary interventions designed to support persons with disabilities to “attain and maintain maximum independence, full physical, mental and vocational ability, and full inclusion and participation in all aspects of life”.¹ Rehabilitation interventions should not merely focus on the attainment of physical or mental health, but should also be involved in strengthening independence and opportunities for participation. The Convention supports the development of community-based rehabilitation, viewing this as key in ensuring access to appropriate services for persons with disabilities living in rural and impoverished communities.²

It is recognised that health and rehabilitation outcomes are not only affected by health care or access to services.³ These outcomes are affected by complex and multifarious factors linked to the social determinants of health, which include a range of social, political, economic, environmental, and cultural factors. Economic variability or instability impacts on the ability of persons with disabilities to achieve better health and rehabilitative outcomes. In turn, this impacts negatively on their ability to enter or re-enter education and, ultimately, to transition into livelihood development.⁴

Inter-sectoral action requiring the inclusion of sectors in addition to the health sector is required when designing and implementing public policies and programmes to improve quality of life and well-being.³ Insufficient inter-sectoral collaboration when designing rehabilitation programmes and services in South Africa continues to disproportionately affect persons with disabilities. They continue to experience “high rates of poverty and poor health, low educational achievement and few employment opportunities”.⁵ Societal attitudes, beliefs and misconceptions are some of the largest challenges facing persons with disabilities;⁶ negative social attitudes tend to view persons with disabilities as lacking agency⁷ and, consequently, as socially invalid.⁸ Several scholars recognise a correlation between the difficult circumstances faced by persons with disabilities and the ways

in which disability is socially positioned.⁷⁻⁹ Negative attitudes towards disability are “a product not only of individual beliefs but also of societal and organisational practices”.⁶

This chapter considers the interplay between negative attitudes towards persons with disabilities, the accountability frameworks that govern the provision of rehabilitation and disability inclusion, and the real-world circumstances of persons with disabilities in South Africa. Discussion focuses on the ways in which rehabilitation and development programmes shape societal attitudes towards persons with disabilities and entrench beliefs about their capabilities, value, and status. It is suggested here that planning, monitoring and evaluation of service delivery for persons with disabilities must be designed to focus on long-term, holistic well-being and not merely ‘impairment management’. This chapter offers three suggestions for shifting perspectives in rehabilitation, namely including persons with disabilities as valued stakeholders; critically evaluating the training curriculum for rehabilitation workers; and moving from a ‘resource-centred’ approach^b to a ‘person-centred’ approach^c in the design, implementation and evaluation of rehabilitation and development services.

The authors have a wealth of experience in the disability sector ranging from direct involvement in the delivery of rehabilitation services, programme design, monitoring and evaluation, and personal experience of accessing rehabilitation and development services. This chapter suggests that a medicalised and resource-centred approach in rehabilitation does a disservice to persons with disabilities in their pursuit of well-being^d as such an approach does not promote the full socio-economic participation of persons with disabilities.

Health and socio-economic context for persons with disabilities

Legislative framework

The South African government has developed legislation and policies in the spheres of health, education, and employment that emphasise consideration, participation and inclusion of persons with disabilities. Key pieces of disability-related legislation and policy include the White Paper on the Rights of Persons with Disabilities,¹³ the Employment

- a Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and efficient participation in society on an equal basis with others.¹
- b ‘Resource-centred’ approach refers to planning based on available resources, rather than on research into the real needs of potential service users.
- c A person-centred approach takes the position that people’s desires, values, family situations, social circumstances and lifestyles need to be considered when planning interventions. Overall, persons or beneficiaries of services need to be consulted and included alongside professionals in the development of appropriate services and solutions. There is an emphasis not just on the activities but also the relationship between the professional and the beneficiary. Historically, beneficiaries were expected to be silent recipients who fitted in with the routines and practices that health and social services deemed most appropriate, but the person-centred approach advocates for flexibility to meet people’s needs in a manner that is best for them and that endeavours to seek holistic wellness.^{10,11}
- d Sen¹² defines well-being as having the freedom to make choices from available resources, having actual opportunities, and acting effectively. The process of converting available resources into well-being is dependent on individual, social, and environmental features.

Equity Act,¹⁴ and the related Code of Good Practice for the Employment of Persons with Disabilities.¹⁵ These policies and pieces of legislation identify the need for the fuller integration of persons with disabilities, and acknowledge their right to education, employment and health care.¹⁶ The definitions of disability found in these policies recognise the role of society in creating disabling environments. Despite this progressive legislative framework, the vast majority of South Africans with disabilities, and particularly those who are historically disadvantaged, face significant challenges in accessing employment or opportunities for livelihood development.^{4,17,18}

Employment

The 2016 Community Survey by Statistics South Africa shows that 41% of persons with disabilities are illiterate compared to 18% among persons without disabilities.¹⁹ This high level of functional illiteracy among persons with disabilities is the consequence of a lack of educational opportunities for children with disabilities.¹⁹ Youth with disabilities who do achieve basic education often face challenges in completing their high school education and in entering tertiary education.^{4,20}

Unemployment rates for persons with disabilities in the formal sector are still considerably higher than rates for non-disabled persons in South Africa.^{17,18} Currently, 1.1% of the employed workforce in South Africa are persons with disabilities, despite the 2% target set by the government.²¹ Factors influencing the employment or underemployment of persons with disabilities in South Africa start with and include the education they have received, the age of onset of their disability, severity of impairment, negative attitudes towards disability, and the complex intertwining of race, gender, geographical location, poverty and disability, which impact on factors such as access to assistive devices and tertiary education.²² In addition, recruitment processes are often difficult for persons with disabilities to navigate, reasonable accommodation is lacking, and programmes focused on integrating people with disabilities into the workplace and retaining employees with disabilities are inadequate.¹⁸

COVID-19 and inequality

Evaluating South Africa's burden of disease is important when considering the effect of disparate access to health care²³ on the acquisition of employment or economic empowerment. Presently, the global COVID-19 pandemic has added to and exacerbated South Africa's quadruple burden of disease and is exposing and deepening inequality.

At the core of the disability rights and labour rights movements is social dialogue and participation.²⁴ During a crisis such as the COVID-19 pandemic, a range of views from governments, worker and employer organisations, and organisations of persons with disabilities, bring a multiplicity

of solutions.²⁴ This suggests collective engagement and networking to facilitate the re-imagination of labour practices. For this to happen, the application of international labour standards and other human rights instruments is essential, in particular application of the UN CRPD.²⁴

Rehabilitation and approaches to disability

Organisations providing rehabilitation and development services play a key role in supporting persons with disabilities as they navigate challenges related to socio-economic participation and inclusion.^{25,26} Current practices that support the drive towards socio-economic inclusion for persons with disabilities in South Africa include increased training and skills development opportunities, regulatory and obligatory legislative and employment mandates, and monitoring and evaluating how persons with disabilities participate, particularly in the economy. However, these approaches tend not to be participative or empathetic to persons with disabilities, and they often do not consider the complex intersection of employment, health and well-being.^e Persons with disabilities are often treated or targeted as passive recipients of health and/or social services, which negatively impacts the way in which persons with disabilities are viewed in society, their access to equal opportunities, as well as their sense of self and social belonging.^f

In South Africa, rehabilitation programmes and services, in particular those focused on vocational training, soft skills, and social work support, are largely offered by non-profit organisations reliant on public and private funding streams in order to provide these interventions at no cost. Many of these organisations have existed for decades and have their origins in traditional welfare approaches to service delivery, a colonial legacy that in many ways continues to influence their operations.⁴ A connection between rehabilitation services and welfare persists in South Africa. Many rehabilitation organisations include a mixture of paradoxical elements as the residue of traditional welfare mingles with a growing recognition of disability as a human rights issue.

This situation is not unique to the South African context, and its impact on how persons with disabilities are viewed in society has been widely critiqued by scholars.²⁷⁻²⁹ These scholars assert that the links binding disability, rehabilitation, and welfare are maintained by understanding disability as a problem of the individual body and as a 'personal tragedy'.²⁶⁻²⁹ In a strong critique of the role of traditional charitable organisations, Drake²⁷ asserts that where these organisations refer to 'empowerment', they are usually referring to the overcoming of an individual deficit and

e Ebrahim A. Traversing disability: Considering social capital in disability inclusive practices. Unpublished thesis, University of Cape Town, 2020.

f Botha M. Blindness, rehabilitation and identity: A critical investigation of discourses of rehabilitation in South African non-profit organisations for visually impaired persons. Unpublished thesis, University of Cape Town, 2020.

not to a process whereby persons with disabilities enter roles of power in society. Scholars suggest that 'need' is often narrowly defined within rehabilitation, framed by an understanding of impairment as individual bodily deficits that must be managed, with little consideration for either socially engendered discrimination or the psycho-emotional impact of encountering such discrimination.^{27,28} In addition, several scholars have argued that a connection between rehabilitation services and charity influences the public perception of persons with disabilities, presenting an image of persons with disabilities as passive recipients of professional and public goodwill.^{8,28} Charitable appeals for donations tend to position persons with disabilities as lacking capability. This positioning has serious consequences for whether persons with disabilities are recognised as able to be active agents in their own lives, and may also impact their personal sense of self, value and capability.^{e,8}

The acquisition of various skills and techniques, and access to assistive devices and other support, are essential for strengthening the capability of persons with disabilities. However, critics suggest that these services and the rehabilitation professionals who provide them are largely divorced from disability politics, including discussions concerning identity, inequality and self-representation, and as such may unintentionally strengthen narrow social attitudes towards persons with disabilities and hinder their recognition as full and equal citizens.^{27,29}

Re-imagining rehabilitation outcomes

In order to promote greater disability inclusion, it is suggested that three focus areas be used to shift from a medical, health and welfare perspective in rehabilitation, to a holistic approach that considers the complexity and intersection of economic empowerment, health and overall well-being of persons with disabilities. These focus areas include recognising and including persons with disabilities as key stakeholders in the rehabilitation process; critically evaluating the curriculum for the training of new rehabilitation workers; and contextualising the design and implementation of rehabilitation services by shifting from a resource-centred approach to a person-centred approach and thereby redefining the outcomes of rehabilitation services to include qualitative indicators.^{g,h,30}

Including persons with disabilities as key stakeholders in the rehabilitation process

There is a disjuncture between the stated purpose of rehabilitation services (to empower persons with disabilities for economic and social inclusion) and the ways in which

those who turn to these services for support tend to be positioned. It is important to consider how the positioning of persons with disabilities as 'receivers of welfare' rather than valued stakeholders may influence whether they are viewed as capable of exercising agency and being active in the economy, as well as whether the development of self-determination is viewed as an important outcome in rehabilitation. These are important aspects for strengthening persons with disabilities in being able to exercise self-advocacy as they navigate a largely inaccessible world and negative social attitudes that may impede their access to equal opportunities.^{e,f}

In a recent study, which included in-depth interviews with visually impaired service users, Botha^f found that while rehabilitation interventions provide invaluable techniques for adjustment to sight loss, individuals feel that they are not recognised as stakeholders in their own processes of development. This impacts on the kinds of services and support that individuals receive. In a study involving persons with physical impairments, Ebrahim found that reduced autonomy and agency are prevalent in those seeking employment or economic inclusion. We must consider how an overwhelming focus on managing impairment in rehabilitation might overlook the development of other key, albeit less easily measured, attributes such as self-determination, resilience and personal networks.

Recognising and including persons with disabilities as stakeholders in rehabilitation services must involve openness on the part of rehabilitation organisations and professionals to critically interrogate and disrupt present power dynamics in rehabilitation. In practical terms, this should involve: creating spaces where the voices of those undergoing rehabilitation interventions can be heard; including persons with disabilities on management boards and in organisational strategic planning; and having collaborative discussions about individual intervention plans that include beneficiaries (and their families) and that acknowledge them as experts in their own lives. Given that experiences of rehabilitation have been found to be significant in shaping the self-perception of persons with disabilities,^{e,8,31,32} the implications of being viewed and treated as either a welfare recipient or an active participant are potentially far-reaching.

Curriculum and training of new rehabilitation workers

The Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020³³ clearly acknowledges that health and rehabilitation providers lack awareness, knowledge and training with respect to the challenges, needs and rights of persons with disabilities. The Framework highlights that negative attitudes towards persons with disabilities obstruct their participation in health and

g Brand D. Inconvenient participation: Persons with disabilities explain the psycho-emotional impact of sport participation in the Western Cape, South Africa. Unpublished thesis, University of Cape Town, 2020.

h Fischer Mogensen K. Employment support services: Facilitating formal employment of persons with disabilities in South Africa. Unpublished thesis, University of Cape Town, 2020.

rehabilitation services. This clear critique of rehabilitation professionals is followed by a recommendation that healthcare providers be trained. Chapter 4 of the World Health Organization Report on Disabilities³⁴ suggests that training of rehabilitation providers (such as occupational therapists, physiotherapists, speech and language therapists and community rehabilitation workers) should include an overview of relevant national and international legislation, including the UN CRPD, which promotes client-centred approaches and shared decision-making between persons with disabilities and professionals. It is suggested that curricula be made more relevant to the needs of persons with disabilities by including content on community needs, using appropriate technologies, and using progressive education methods, including content on the social, political, cultural, and economic factors affecting the health and quality of life of persons with disabilities. In South Africa, authors such as Amosun et al.³⁵ and De Jongh³⁶ advocate for curriculum review and change that considers political engagement and issues such as marginalisation, exploitation and powerlessness that limit equitable access of persons with disabilities to opportunities and resources. Recent demands for the decolonisation of health and rehabilitation curricula in South Africa present challenges to students, academics and professionals. The call for curricula change, however, also offers an opportunity to deepen shared understandings and development of knowledge and practices that are participative and inclusive. Amosun et al.³⁵ suggest that using this opportunity for change and transformation will strengthen the South African healthcare system by ensuring that rehabilitation professionals are prepared to provide services that acknowledge the uniqueness of South African persons with disabilities, and by creating programmes that are transformative.

Shifting from resource-centred to person-centred approaches

A central challenge in terms of the impact that disability-related programmes and services have in South Africa is that planning, monitoring and evaluation are pivoted towards tracking indicators related to the expenditure of resources rather than to whether services are achieving any long-term change in people's lives. Rehabilitation and vocational programmes are key in terms of how persons with disabilities move forward in the pursuit of economic stability. However, the current revolving door, which sees persons with disabilities remain in a cycle of training and short-term employment, stifle the goal of achieving gainful and long-term employment. The revolving door perpetuates the idea of reliance on these programmes, while not encouraging persons with disabilities to make self-determined choices in terms of their economic inclusion.

While measuring resource-related indicators is important, a 'resource-centred' approach to planning, implementation, monitoring and evaluation of rehabilitation services does not consider or provide information on the well-being of the beneficiaries. Instead, it focuses on quantitative output and short-term outcomes of impairment management. In

contrast, aspects such as the development of social capital, self-determination and personal fulfilment are qualitative indicators of change over time, but often these do not receive attention when interventions are measured or evaluated.^e To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and realise aspirations, satisfy needs, and change or cope with their environment. These qualitative indicators are, therefore, crucial for understanding what rehabilitation services do (and perhaps neglect to do) in the lives of persons with disabilities in terms of whether they strengthen individuals to access economic empowerment, social inclusion, and equal access to health care and other services. Monitoring rehabilitation services should be understood not only as a means to ensure accountability for resources, but as essential for ensuring that programmes are accountable for actual positive changes in the well-being of persons with disabilities and their ability to participate in all spheres of life.^{g,h,30}

When designing rehabilitation programmes we must consider how disability is being viewed. This also becomes pivotal in terms of how programme impact will be evaluated. One important critique made of the monitoring process in the UN CRPD is: "who gets to define the factors or statistical indicators for collecting data" and who decides on how disability is defined?³⁷ Accuracy of monitoring outcomes for persons with disabilities is sensitive to how disability is positioned within any rehabilitation intervention. Regular evaluations of interventions aimed at reintegrating persons with disabilities into active citizenship should share a core goal, namely of working towards persons with disabilities enjoying equal access to all aspects deemed essential to a state of well-being. As such, well-being should be defined by persons with disabilities themselves and what it means to the individual in his or her context.¹²

The need for qualitative and holistic evaluation

The critique around current rehabilitation services has identified that the approach and planning of programmes and interventions tends to stem from a medicalised perspective, which views disability as a problem of the individual impaired body.²⁹ The suggestion made in this chapter is that while 'impairment management' remains a core function of rehabilitation,^{7,32} the medicalised focus of these rehabilitation services must be disrupted. A person-centred approach that draws on the lived experience of persons with disabilities will provide a more nuanced perspective in order to ensure that the complexity of the lived experience of persons with disabilities (including impairment-related difficulties and socially engendered discrimination) are understood.^{7,37}

This holistic approach needs to consider the basic needs and impairment management of persons with disabilities, but it must also set the tone for social and economic inclusion into the community. The idea of disrupting the status quo of rehabilitation services also involves the discussion of stakeholder roles. It is necessary to talk about issues of power and privilege within these organisations. Currently a power imbalance still exists between non-impaired persons and persons with impairments. This calls for a participatory approach to this suggested disruption in the design of rehabilitation services. Within these service organisations, issues of systemic oppression have played an immense role in the experience of persons with disabilities and their belief in their own value and sense of belonging. Understanding how persons with disabilities experience the rehabilitative process should be a core part of how we monitor, measure and value public sponsored interventions for economic and social inclusion of persons with disabilities.

Conclusion

Taking a position on a more expanded view of disability and its core aspects is important as we advocate for the expansion of accountability frameworks governing rehabilitation and development interventions and the impact focus of such interventions. While designing indicators that measure both tangible and intangible outcomes is certainly challenging, this is essential if rehabilitation interventions are to take responsibility for facilitating the development of holistic well-being and greater socio-economic inclusion for persons with disabilities, rather than merely presenting short-term indicators related to the management of impairments alone.

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