

# South African Health Review

---

2020

# A transformative approach to disability awareness, driven by persons with disability

Sandy Heyman, Dhanashree Pillay, Victor de Andrade, Ronel Roos, Kganetso Sekome



Two-fold transformation includes empowering persons with disabilities to be educators, and transforming the views and perceptions of students in therapeutic professions at institutions of higher learning.



## The aim

This chapter uses the World Health Organization's International Classification of Functioning, Disability and Health (ICF) to explore how the therapeutic professions view disability. The chapter goes on to present the PADI (People for Awareness of Disability Issues) project as an example of an experiential teaching-and-learning approach, facilitating implementation of disability policies and practices in a community of practice.



## Key findings

A role reversal occurs when persons with disabilities become educators and providers of a service rather than recipients of a service; this reversal enriches student clinicians' knowledge and understanding of disability and shifts it from theory to practice.

Disability-awareness programmes based on participation, community of practice, experience, and context can be transformative for persons with disabilities, student clinicians, and academic staff.



## Recommendations

As professional programmes transform, there are opportunities for inclusive and wide-ranging transformation:

- Projects like PADI should be included in curricula and persons with disabilities should be incorporated as educators; this in turn gives student clinicians an appreciation of the lived experience of disability.
- When reviewing and adjusting therapeutic profession curricula, persons with disabilities should be invited to form part of the teams reviewing and updating said curricula.
- Student learning should be dynamic and inclusive, with agency also resting in the persons with disabilities, and recognition given to their knowledge, insight, value, and power.



# Reducing psychosocial disability for persons with severe mental illness in South Africa

Mvuyiso Talatala, Enos Ramano, Bonginkosi Chiliza



Recommendations to reduce psychosocial disability include management of mental illness in the workplace, establishment of recovery-oriented mental health services, prioritisation of South African research on mental health.



## The aim

To describe the association between psychosocial disability and severe mental illness (SMI), and to explore some of the key challenges of mental health and disability.



## Key findings

There is inadequate epidemiological data on SMI and psychosocial disability in South Africa. Assessment of impairment and the determination of psychosocial disability are complex and at times difficult to perform. Psychosocial disability has a negative economic impact on persons with mental illness, governments, employers, and society. Stigma and lack of psychosocial rehabilitation remain a challenge for persons with mental illness.



## Recommendations

South Africa should move towards equitable access to health care for persons with mental illness. Early intervention recovery-oriented services must be established. Workplace environments that are much more willing to accommodate persons with mental illness must be built. There must be prioritisation of South African research on mental health. Legislative and policy improvements are necessary, especially with regard to the Medical Schemes Act (No. 131 of 1998).



# Improving the health of children and adults with intellectual disability in South Africa: legislative, policy and service development

Sharon Kleintjes, Judith McKenzie, Toni Abrahams, Colleen Adnams



Policy data from this review reflect a need for improved policies on early detection, identification and intervention in the case of children with, or at risk for intellectual and developmental disabilities.



## The aim

This scoping review provides a 10-year country-level overview of relevant legislation and policy, services, training and capacity development, and advocacy to promote the health and wellbeing of persons with intellectual disability (ID).



## Key findings

- Improved policies on early detection, identification and intervention are needed for children with, or at risk for ID.
- Deinstitutionalisation policy promotes community-based mental health care, but funding has not followed to ensure quality care.
- Supported employment increases social inclusion, skills and income.
- Poorly supported caregivers may leave employment, deepening family poverty.
- Caregiver stress is associated with lack of respite, inadequate support, and limited involvement in decision-making.
- Caregivers may have low levels of health literacy and practical skills.
- Provider partnerships with caregivers and people with ID can promote empowerment.



## Recommendations

- Review outdated legislation and terminology, and develop dedicated disability legislation.
- Prioritise reduction in preventable causes of ID, as well as early identification and intervention.
- A family-centred approach is needed, emphasising community-based health-related supports.
- Support capacity-building of caregivers.



# Health legislation and policy:

## a focus on disability

Andy Gray, Yousuf Vawda



Viewed from the perspective of persons with disabilities, much of the existing legislation appears to pay little more than lip-service to South Africa's international obligations and the fine promises entrenched in the Constitution and the National Health Act.



### The aim

To provide a brief, but critical, examination of the legislative and policy steps taken to address universal health coverage, with particular emphasis on equity and the extent to which adequate provision is made for the services needed by persons with disabilities. The chapter also provides a brief summary of selected health-related secondary and tertiary legislation and discusses major health-related jurisprudence.



### Key findings

In many ways, 2020 has been a year 'on hold', with specific major health-related legislative processes delayed or in abeyance. Viewed from the perspective of those with disabilities, much of the existing legislation appears to pay little more than lip-service to South Africa's international obligations and the fine promises entrenched in the Constitution and the National Health Act. The slow progress with regard to health equity for disabled persons is a sad commentary on the failure of both distributive justice and the protection of human rights.

Due in part to the disruption caused by the COVID-19 pandemic, progress on the National Health Insurance Bill has been limited.



### Recommendations

If the resources required to ensure the integration of services signalled in the Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020 are to be mobilised and equitably applied, they need to be explicitly referenced in the benefit package to be delivered under National Health Insurance.



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

Hannah Kuper, Jill Hanass-Hancock



The persistent health inequity experienced by persons with disabilities can perhaps most fundamentally be attributed to a lack of relevant data to inform planning.



## The aim

The intention of this chapter is to frame the debate on how to achieve equitable healthcare coverage for persons with disabilities in South Africa. To achieve this, a review was done of the needs and access gaps experienced, the drivers of inequity, and potential levers and solutions to resolving these issues.



## Key findings

Persons with disabilities in South Africa continue to have inequitable access to health care, as they experience a range of additional barriers when seeking care (access, informational, attitudinal, and/or financial barriers). An increased focus on persons with disabilities is needed urgently if the country is to achieve Universal Health Coverage. Pockets of good practice exist that can inspire thinking on ways to improve health-service access.



## Recommendations

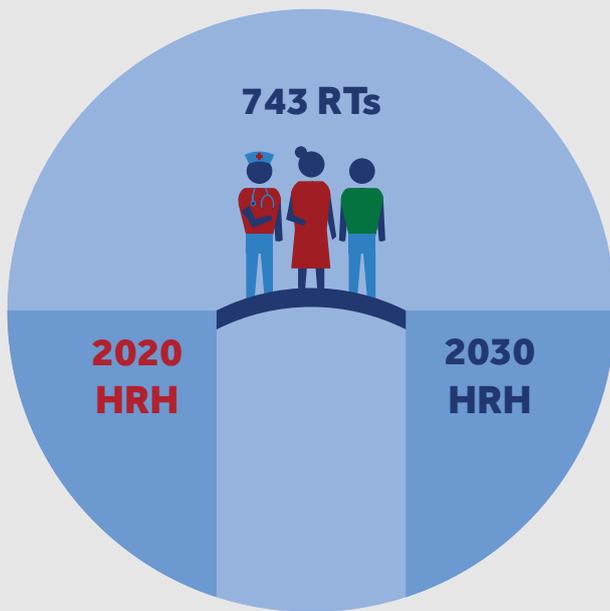
Greater levels of political will, leadership, and funding are required to implement the robust disability-inclusive policies and plans that exist in South Africa. It is crucial to improve the amount and quality of data on disability-inclusion through monitoring and research. This will help to identify and address key gaps, and aid understanding of what improves service provision for persons with disabilities.



# HRH planning for rehabilitation services:

a focus to reduce inter-provincial inequities

Ritika Tiwari, Lieketseng Ned, Usuf Chikte



Policymakers should plan, create posts, and deploy trained professionals using equity-based HRH forecasting.



## The aim

Public sector rehabilitation workforce planning in South Africa is inadequate and the impact is reflected in critical human resource shortages, maldistribution of these resources, and limited access to rehabilitation services. The aim of this chapter is to estimate gaps and project additional need from 2020 to 2030 for the three rehabilitation therapist (RT) categories, using an equity-based HRH planning approach to reduce existing inter-provincial inequities.



## Key findings

To maintain the current inter-provincial density of occupational therapists, speech therapists and audiologists, and physiotherapists (forecasting historical growth trends), an additional 743 RTs will be needed. To increase workforce ratios in the three lowest-scoring provinces would require an additional 837 RTs, and in the six lowest-scoring provinces this would require an additional 1 214 RTs. Meeting international benchmarks would require 42 523 RTs.



## Recommendations

In the short-term, training of discipline-specific mid-level workers should be re-instated. In the mid-term, community-based rehabilitation workers should be supported and trained to enable work across traditional health and social service boundaries. In the long-term, policymakers should plan, create posts, and deploy trained professionals as per the equity-based HRH forecasting exercise undertaken in this study. Lastly, national training capacity should be built.



# Social security benefits and disability assessment in the working-age population in South Africa

Blanche Andrews, Shahieda Adams



Evaluation of disability in the working-age population is key in accessing benefits in South Africa's social security framework.



## The aim

In addition to access to core health services, persons with disabilities require access to services providing for the medical assessment of disability. These assessments form the gateway to accessing various social security benefits. The chapter looks at medical assessment of disability across social security structures.



## Key findings

Medical assessment of disability takes place within the broader context of the legislative and social security framework. In this sense it is not only a medical process but includes legal and administrative components. Assessments are not performed in a uniform manner across the different social security benefits. There is a paucity of detailed data and critique related to the assessment process in the South African setting.



## Recommendations

A framework is outlined for disability assessment across social security benefits. These assessments should focus not only on compensation but also on the integration of persons with disabilities into the workforce and society, thereby aligning the disability-assessment process with the principles outlined in the United Nations Convention on the Rights of Persons with Disabilities. Adoption of the framework will enhance the quality of medical assessments performed and allow for a more standardised and inclusive approach to disability evaluations across all social security benefits.



# Perinatal depression and anxiety in resource-constrained settings:

interventions and health systems strengthening

Simone Honikman, Siphumelele Sigwebela, Marguerite Schneider, Sally Field



Perinatal mental health services can be integrated into maternal and child health services in resource-constrained settings and may function to strengthen the health system.



## The aim

This chapter describes select service implementation examples from low- and middle-income countries providing interventions for perinatal depression and anxiety. The aim is to analyse these interventions with regard to how they adhere to good practice guidelines and how they strengthen the health systems in which they are located.



## Key findings

The three cases described in the chapter are the Maternal Mental Health Project (Uganda), the Perinatal Mental Health Project (South Africa), and the Thinking Healthy Programme (Pakistan). The projects used stepped-care, multi-component care and collaborative care models integrated within maternal and child health services, and drew on evidence-based intervention elements. Workforce strengthening occurred through training and supervision. Ministry of Health partnerships supported the sustainability and scalability of the interventions.



## Recommendations

- Perinatal mental health services should be integrated into maternal and child health services in resource-constrained settings.
- To ensure quality and effectiveness of these services, the following need to be addressed:
  - Health workforce strengthening through a range of capacity-building and supportive approaches.
  - The design of interventions that simultaneously address both social determinants and psychological distress.
- For scale up of these services, the following need to be addressed:
  - The availability of targeted health financing.
  - The development of relevant mental health targets and indicators integrated within the Health Information System.
  - The development of mechanisms to support leadership and governance of the health system.



# Community-based peer supporters for persons with disabilities: experiences from two training programmes

Gillian Saloojee, Maryke Bezuidenhout



Peer supporters assist in addressing some of the inequities in access to rehabilitation, particularly in resource-constrained settings.



## The aim

This chapter describes the development and implementation of peer-supporter-led training programmes by two non-profit organisations. Parents of children with cerebral palsy (CP) and adults with spinal cord injuries (SCIs) respectively were trained and employed by Malamulele Onward, and the Manguzi-based Siletha Ithemba.



## Key findings

Formal and informal evaluation of both programmes demonstrated their value. The Malamulele Onward trained parent facilitators assisted caregivers to understand CP, and helped them learn how to care for their children in helpful ways and how to transform a sense of hopelessness, isolation and guilt into pride, acceptance and increased self-confidence. Clients with newly acquired SCIs experienced easier inclusion and integration back into family and community settings. Peer supporters also assisted in addressing some of the inequities in access to rehabilitation, particularly in resource-constrained settings.



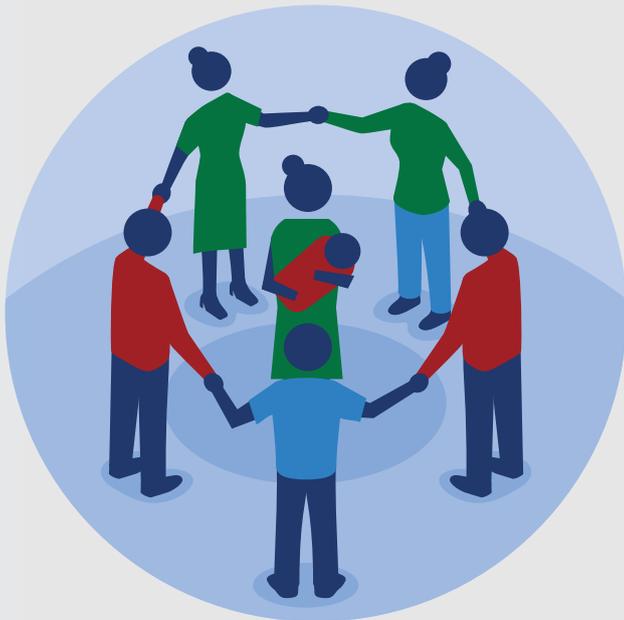
## Recommendations

- Funding is required. Peer-supporter micro-enterprises that contract to government departments and other service providers are one option for long-term sustainability of peer-supporter programmes.
- Professionalisation and accreditation of the training, for example via a qualification with the Quality Council for Trades and Occupations, would make peer supporters more employable and guarantee the quality and standard of training.
- For peer supporters to work independently, creative transport solutions are needed.
- Integration of peer supporters into existing rehabilitation services requires attitudinal change among professionals, and recognition of the expertise of 'non-professionals'.
- Exposure to successful peer-supporter programmes at undergraduate level may assist in ensuring that rehabilitation services are more inclusive.



# Early childhood intervention: the Gauteng experience

Sadna Balton, Annika Vallabhjee, Elma Burger



Young children with disabilities often miss out on intervention services and family support in the first few critical years of life.



## The challenge

In Gauteng, services to children have traditionally been offered in a fragmented, siloed approach across levels of service delivery. This has resulted in children at risk for or with developmental delays and disability being identified and referred late for intervention.



## The aim

This chapter aims to provide an overview of the process of developing an early childhood intervention (ECI) workgroup, and to highlight activities undertaken by the workgroup to facilitate improved services to children and their families in Gauteng.



## Key findings

Challenges experienced by therapists working in the field include lack of guidance and leadership, late identification and referrals, poor intersectoral collaboration, and the need for capacity building. Solutions to address the identified concerns include:

- Development of an ECI policy
- Guide to getting started document
- Stakeholder engagement
- Workshops and conferences
- Resource development



## Recommendations

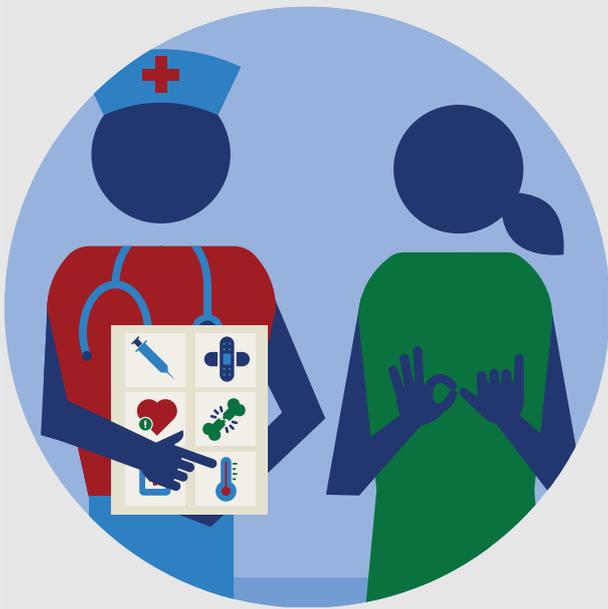
In order to progress the ECI agenda in Gauteng it is critical that the proposed policy be finalised, adopted and implemented. ECI should become a national priority at policy level, with appropriate indicators to hold all stakeholders accountable.



# Communication vulnerability in South African health care:

the role of augmentative and alternative communication

Kirsty Bastable, Shakila Dada



Individuals with communication vulnerability are at risk for decreased participation in the healthcare system, leading to an increased risk for adverse events and a lack of treatment adherence.



## The aim

This chapter reviews the literature on use of augmentative and alternative communication (AAC) among individuals with communication vulnerability in healthcare settings. The results are discussed in relation to the South African context, and recommendations are made for policy and practice.



## Key findings

AAC provides a successful mechanism for patients to communicate with healthcare workers in intensive care, general health care and dental health care. Both high-technology and low-technology AAC were implemented successfully, and staff and patients were positive overall about the effects of AAC.



## Recommendations

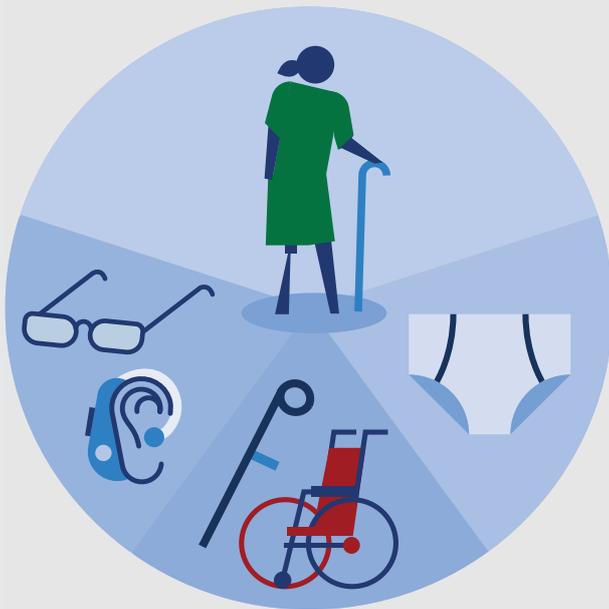
AAC can provide a mechanism of communication for patients who are unable to speak either permanently or temporarily. Use of AAC could benefit not only individuals with disabilities but also those with low literacy, and those with cultural and language differences from their healthcare providers. In the South African context, low-technology AAC is proposed as a feasible option, but changes are required at all levels for this to be successful



# Assistive technology service delivery in South Africa:

## conceptualising a systems approach

Surona Visagie, Elsje Scheffler, Nikola Seymour, Gubela Mji



Assistive technology services and products are essential to many persons with impairments, as they enable participation in life roles and community integration.



### The aim

The aim of this chapter is to review assistive technology (AT) service provision in South Africa using a systems-approach lens and to provide recommendations for future AT services that build on current best practice strategies and international best practice guidelines.



### Key findings

AT services in South Africa are not guided by comprehensive, overarching national policy. Current services are hampered by financial constraints; insufficient numbers of and inadequately trained service providers; variation in provision among different provinces, between levels of health care, and across geographical areas; barriers in procurement and delivery systems; and inadequate integration of AT services.



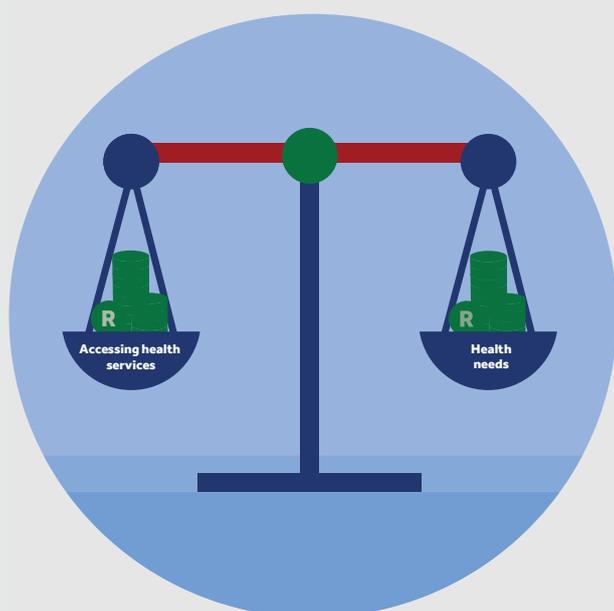
### Recommendations

The development of integrated, intersectoral policy for accessible, equitable, person-centred AT services is recommended. This must be monitored and evaluated through assessing user outcomes, under guidance of the National Department of Health. Important focus areas include stimulation of local product design and manufacture, specified ring-fenced budgets, a heterogeneous provider corps that can provide a range of products at district level, communication and collaboration between different stakeholder groups, identification and upscaling of clinical good practice models, and a collaborative research and dissemination agenda.



# Health-system strengthening that matters to rural persons with disabilities: lessons from the Eastern Cape

Kate Sherry, Steve Reid, Madeleine Duncan



Persons with disabilities are known to experience marginalisation in both the health system and broader society, often for related reasons, such as environmental barriers, increased risk of poverty, and social exclusion.



## The aim

This qualitative, ethnographic study aims to understand how persons with disabilities and their households living in a remote rural area make decisions about engaging with the healthcare system, how they experience this engagement, and how this process unfolds over time in the context of their everyday lives.



## Key findings

Decisions of persons with disabilities and their families around seeking healthcare are complex, weighing up the multidimensional costs of service access against the functional and economic costs of the health complaint, and the perceived likelihood of receiving help. Healthcare workers' often limited understanding of disability and the life context and lived experience of participants have a strong negative impact on the quality and effectiveness of care. At the same time, the findings revealed the unexpected power of person-centred engagement offered by certain healthcare workers, which can outweigh serious system defects in meeting the needs of persons with disabilities.



## Recommendations

A range of health system measures is proposed that support and promote person-centred, context-sensitive healthcare practice. These include exposure of facility-based health professionals to community context (e.g. through regular outreach), decentralising of disability services to build capacity at community level, and longitudinal relationships between healthcare workers and persons with disabilities, among others.



# The role of social workers in addressing caregiver burden in families of persons with disabilities

Noreth Muller-Kluits, Ilze Slabbert



By facilitating access to necessary resources that assist both the person with disability and his/her family, social workers can also relieve the caregiver burden often experienced by family members as informal caregivers.



## The aim

The aim of this chapter is to explore the burdens experienced by family caregivers in the rehabilitation and care of persons with disabilities. The chapter also evaluates how social workers can help to address caregiver burden in a South African context.



## Key findings

- A Cape Town study of family caregivers of persons with physical disabilities found that family caregivers experience various caregiver burdens, including physical, emotional, financial, and social.
- Social workers have an important role to play in multi-disciplinary team service delivery to persons with disabilities and their families. They are guided by policies such as the White Paper on the Rights of Persons with Disabilities (WPRPD).
- Specific social work roles, such as educator, broker and enabler, help in addressing caregiver burden.



## Recommendations

- Implementation of the WPRPD, especially pillars 3 and 4, will assist with the integration of persons with disabilities into society, providing more respite time for caregivers. This could, in turn, address certain caregiver burden concerns, such as lack of employment opportunities.
- Advocacy on the specific roles of social work in the disability sector would increase awareness of support available to family caregivers to relieve some of the caregiver burden.
- Social workers' holistic consideration of the individual in context, along with the role they play in the community, are just some of the expertise that could be advocated and strengthened in the disability sector.



# Disability inclusion in the Northern Cape: a community-based wheelchair service project

Ronique Walters, Maria Britz, Erna van der Westhuizen



Persons with long-term physical impairments require a mobility device to access resources within their communities and to become active members of society. The wheelchair, therefore, serves as a tool facilitating the inclusion of persons with disability into their communities.



## The aim

The aim of the study was to implement a community-based outreach seating model in order to improve wheelchair service provision and access in the Northern Cape.



## Key findings

- Lack of funding to address shortfalls in local government budget.
- Lack of trained rehabilitation therapists available to provide sustainable wheelchair seating services.
- Lack of provider and client awareness in terms of referral pathways and how to action them, in order to access services.



## Recommendations

- Capacitate local government service providers to ensure systems change and sustainability of quality wheelchair service provision.
- Understand community context in order to establish formal referral pathways and improve service access.



# Toward 'Rehab 2030': building on the contribution of mid-level community-based rehabilitation workers in South Africa

Susan Philpott, Pam McLaren, Sarah Rule



Unwillingness of professional bodies to register mid-level community-based rehabilitation workers has undermined the training and deployment of this essential workforce.



## The aim

This historical review aims to explore the history of community-based rehabilitation (CBR) workers, with a view to understanding factors that have shaped the current status of CBR in South Africa and how this can provide a platform for the country to achieve the vision of Rehab 2030.



## Key findings

Globally, through the SDGs and Rehab 2030, there has been a growing recognition of the importance of CBR as a means to realise the rights of persons with disabilities. However, over the past 40 years in South Africa various factors have influenced the training and deployment of mid-level community rehabilitation workers (MLCRWs), including shifts in the approach to health, and policy developments that have not prioritised CBR services. Although there was an early alliance between persons with disabilities and rehabilitation therapists, this was not sustained. Further, different understandings of CBR and the unwillingness of professional bodies to register MLCRWs have undermined the training and deployment of a workforce for CBR.



## Recommendations

The chapter recommends that CBR be included in a strategy for health care and that advocacy and dissemination of information on CBR be considered essential. Further, persons with disabilities and their organisations must be included in planning, implementing and evaluating CBR programmes. Additional recommendations concern the re-activation of MLCRW training and the improvement of multi-sectoral collaboration for CBR.



# Reimagining rehabilitation outcomes in South Africa

Adèle Ebrahim, Michelle Botha, Dominique Brand, Karina Fischer Mogensen



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



## The aim

This chapter highlights the need to critically evaluate accountability frameworks governing the provision of rehabilitation and development services for persons with disabilities in order to better meet their complex needs.



## Key findings

Health and rehabilitation outcomes are not only affected by health care and access to services. These outcomes are affected by complex factors linked to the social determinants of health, including social, political, economic, environmental, and cultural factors. Economic instability impacts on the ability of persons with disabilities to achieve better health and rehabilitative outcomes, which in turn impacts on their educational options and livelihood development.



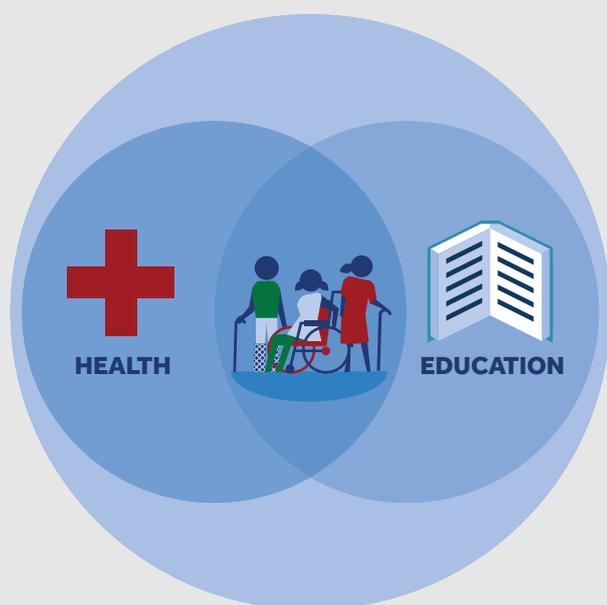
## Recommendations

There is a need to look beyond quantitative outputs and impairment management in rehabilitation, and towards qualitative indicators of holistic, long-term well-being. Recommendations include: recognising and including persons with disabilities as key stakeholders in the rehabilitation process; critically evaluating the curriculum for 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.



# The intersection between Health and Education: meeting the intervention needs of children and youth with disabilities

Alecia Samuels, Unati Stemela, Mpilo Booii



While governments often develop separate departments to manage intervention services, children and youth with disabilities frequently receive overlapping support from these sectors, making the separation of health and education a false dichotomy.



## The aim

This chapter discusses the intersections between the two prominent sectors (Health and Education) that children and youth with disabilities (CYWD) have to traverse in order to access interventions that promote their ongoing health, development and academic achievements.



## Key findings

CYWD are required to access intervention services from a range of professionals within the same sector and across the two sectors. The siloed, medical-model approach within which many intervention professionals are trained, leads to a lack of coordinated intervention. This results in unnecessary duplication and confusion in terms of roles and responsibilities for intervention despite existing intersectoral policies that should give guidance.



## Recommendations

Intervention professionals should use a participatory framework like the ICF to guide collaboration within and across the health and education sectors, while keeping CYWD as the central focus. Practical examples are given to show how this can be achieved.



# Ensuring equal access to health services for the Deaf in South Africa

Leslie London, Virginia Zweigenthal, Marion Heap



Deaf patients using South African Sign Language for communication experience multiple axes of discrimination in accessing quality health care.



## The aim

This chapter explores the recent South African literature for health-system innovations that provide Deaf patients with interpreter services to improve their access to quality health care.



## Key findings

Deaf patients using South African Sign Language (SASL) for communication experience multiple axes of discrimination in accessing quality health care. The lack of professional SASL interpreters in the health services is a key obstacle. Equitable access to health care for the Deaf community will therefore require provision of SASL interpreter services that can address autonomy, confidentiality, empowerment and information sharing. SASL provision may heighten awareness of disability as a human rights issue, to the benefit of other users with disabilities.



## Recommendations

- SASL interpretation services should be provided in the South African healthcare system.
- Provision of adequate SASL interpretation services should be complemented by other programmes that boost the agency of the Deaf and overcome obstacles.
- Prioritisation of SASL interpretation services should focus on services meeting particularly important needs, such as ophthalmology and maternity services.
- Reframing health care within a human rights framework will enable Deaf patients to be active agents in demanding services suited to their needs and achieving a more responsive health system.



# Health and Related Indicators

Candy Day, Andy Gray, Thesandree Padayachee, Annibale Cois



Routine health-information systems are poorly organised and do not allow fine monitoring of health-system access among persons with disabilities, a shortfall that impacts negatively on their health status.



## The aim

The indicators chapter aims to provide a repository of data, at national and provincial level, particularly focused on routine data sources but also capturing major surveys and global reports. While a longer-term focus on the progress towards universal health coverage remains in the background, the key theme in 2020 is equitable access to health care for persons with disabilities.



## Key findings

This chapter shows that routine health information systems, bolstered by representative national surveys, can allow the state of health of the nation to be described and tracked over time. Some sensitive systems have already detected the profound impacts that COVID-19 has wrought. However, routine health-information systems are poorly organised and do not allow fine monitoring of health-system access among persons with disabilities, a shortfall that impacts negatively on their health status.



## Recommendations

Carefully planned disaggregation of routine and survey data can reveal the extent to which persons with disabilities enjoy equitable access to healthcare services, or are denied this right. However, this requires designation of disability status as a dichotomous variable. As progress is made towards implementing National Health Insurance, routine data systems will need to reflect both public and private sector provision of services. COVID-19 has revealed how important timely access to accurate, comprehensive multi-sectoral health data are to effective and agile planning and execution of health interventions.

