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

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Achievement of the Rehab 2030 vision is only possible if stakeholders in the rehabilitation sector unite, particularly in resolving the acute need for human resources.

This chapter discusses community-based rehabilitation (CBR), with a particular focus on mid-level community rehabilitation workers (MLCRWs). The case for CBR was supported by the founding and co-operation of two key stakeholder groups, viz. the Rural Disability Action Group, and Disabled People South Africa. This collaboration has been important in training MLCRWs in varied contexts over the past 40 years. 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. It is recommended that persons with disabilities and their organisations be included in planning, implementing, and evaluating CBR programmes. Additional recommendations made are for the re-activation of MLCRW training, and the improvement of multi-sectoral collaboration for CBR.

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Introduction

'Rehabilitation 2030: a call for action'[1] was launched by the World Health Organization (WHO) in 2017, to strengthen provision of rehabilitation services globally. The call provides an opportunity for South Africa to revisit its history with regard to rehabilitation, to identify factors that have assisted or hindered the provision of appropriate services to date, and to make recommendations regarding the training and deployment of a rehabilitation workforce. This chapter focuses particularly on the contribution that mid-level community rehabilitation workers (MLCRWs) can make to rehabilitation that is accessible and appropriate, in order to ensure universal health coverage and 'rehabilitation for all' under National Health Insurance (NHI). The term 'mid-level community rehabilitation worker' refers to a multi-skilled worker trained to identify persons with disabilities at community level and facilitate intervention in the health sector.[2] A major component of the MLCRW role has been to promote the empowerment and participation of persons with disabilities and their families. MLCRWs have been referred to by different titles in different areas.

Disability is not only a global public health and human rights issue, but also a development priority[3] that disproportionately affects women, older people, and people living in poverty. Globally, it is estimated that 74% of the total number of years lived with disability are due to health conditions that cause limitations in functioning and that can benefit from rehabilitation.[1] Rehabilitation benefits the individual and family as it improves a person's independence, supports his or her ability to return to work and/or other social roles, and reduces costs related to care and support. At societal level, rehabilitation reduces the length of stay in hospital, decreases re-admission rates, and prevents expensive complications.[3,4]

Globally, however, the need for rehabilitation is greater than the services provided; in particular, people in lower- and middle-income countries (including South Africa) tend to have poor access to rehabilitation services.[5] In many countries, health systems do not have the capacity to provide the necessary services.[1] Challenges include insufficient numbers of appropriately trained professionals, ineffective service models, and lack of integration and decentralisation of services.[3] This is compounded by under-utilisation of rehabilitation, which could be attributed to lack of access due to transport challenges and costs of the service (particularly in rural areas), as well as lack of awareness of the importance of rehabilitation.[1]

Rehabilitation and CBR

Rehabilitation has been defined as "a set of interventions designed to reduce disability and optimise functioning in individuals with health conditions, in interaction with their environment".[1] The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) (Article 26) on habilitation and rehabilitation emphasises that these interventions should begin early and be available as close as possible to where persons with disabilities live, including in rural areas.[6]

Community-based rehabilitation (CBR) has been defined as "a strategy within community development for the rehabilitation, equalization of opportunities, poverty reduction and social inclusion of persons with disabilities".[7] The WHO has developed a set of CBR guidelines that identify different components on a CBR matrix, including empowerment and a social component.[7] Rehab 2030 envisages CBR as a means "to realize human rights and development objectives at the community level, based on a comprehensive multi-sectoral approach, which can empower persons with disabilities and their families".[8] CBR is seen to be of particular value in resource-constrained settings, where services can be provided by MLCRWs, with the measure (indicator) of success being the proportion of the population covered by CBR or other community services.[3]

Shift in approach to disability

A major shift has taken place since the 1970s/80s with regard to understanding disability. Historically, disability has been associated with illness and incapacity, with the focus on the 'defect' or 'inability' of a person to perform certain tasks, such as being unable to hear or walk. The 'medical model' of disability is understood as the approach in which medical personnel (surgeons, therapists, etc.) are believed to have sole expertise and therefore to be best placed to take decisions on behalf of persons with disabilities who are seen to be passive and dependent on the expert to provide a cure or care for them.

In the 1970s, an alternative approach was advocated, based on the premise that disability arises not so much from the impairment of the individual, as from barriers in society that serve to exclude him or her from participation. Removal of these barriers is the prime focus of the social model of disability, in which disabled persons are recognised as being the agents of their own development.[9] It follows, then, that empowerment of persons with disabilities is crucial, both in overcoming oppression and powerlessness and in supporting their participation in decision-making. This empowering role has been played by CBR workers.[10]

There has also been growing affirmation of disability as a human rights issue, with discrimination on the grounds of disability being prohibited in the South African Constitution of 1996[11] and confirmed by South Africa's ratification of the UN CRPD. Key international documents affirm that disability is a human rights issue.[7,12]

The inclusion of Article 26 "Habilitation and rehabilitation" in the UN CRPD[6] provides the foundation for a rights-based approach to rehabilitation. The WHO recommends that state parties address barriers to rehabilitation by inter alia increasing human resources, including training and retention of rehabilitation personnel, and expanding and decentralising service provision.[12]

Global disability priorities

The 2030 Agenda for Sustainable Development and the associated 17 Sustainable Development Goals (SDGs) (to which South Africa is a signatory) provide a framework for countries to take action on development priorities.[13] The Agenda undertakes to leave no one behind, including persons with disabilities. Although limited progress has been made, persons with disabilities still encounter numerous barriers to full inclusion and participation in the life of their communities. Barriers include lack of access to essential services, rehabilitation, and support for independent living – all of which are essential to the full and equal participation of persons with disabilities as beneficiaries of development and agents of change.[14]

SDG 3 aims to "Ensure healthy lives and promote well-being for all at all ages". The WHO Global Disability Action Plan 2014-2021 envisages rehabilitation as a key health strategy for achieving SDG 3, as it aims "to optimize functioning and support those with health conditions to be as independent as possible and to actively participate in the society…."[8]

Identification of CBR as a key *health* strategy for achieving healthy lives and well-being seems to be at odds with the definition (above), which describes a *community-development* strategy. CBR is about collective action in partnership with persons with disabilities and their families to address matters of health, education, livelihood, social engagement, and empowerment.[7] The challenge with CBR is to ensure that key sectors work collaboratively and on an equal footing together with persons with disabilities using a developmental approach.

Overview of CBR in South Africa

The development of CBR in South Africa has been influenced by a range of social, economic and political issues, including the alliance of the disability rights movement with the anti-apartheid movement. At international level, the Alma Ata Declaration, the WHO guidelines and the publication of *Disabled Village Children* represented emerging support for CBR.[15-17] The subsequent shift from a comprehensive approach to primary health care (PHC), to selective PHC, which focused on prevention and treatment of a few diseases in ways that could be measured,[18,19] had a negative impact on CBR and its realisation in South Africa. Nonetheless, there were pockets of innovation. Examples include the Prozesky and Draper model, which prioritised the promotion of community involvement through project committees and training of lay community health workers.[20] This subsequently became known as a potential model for future healthcare delivery as part of a wider project of total community development.[20] Unfortunately, the subsequent priority given to a curative, hospital-based approach[20] and selective PHC[20] was also negative for CBR.

CBR was dealt another blow when community health was incorporated into the wider field of public health. In particular, the challenge of measuring the impact of CBR in terms of cost-benefit analysis became a major barrier. This created challenges when attempts were made to measure disability, even though two international classifications of disability were formulated over time.[21,22] It was only in 2015 that a CBR indicator manual was published.[23] Another factor contributing to the loss of valuable experience of rural PHC doctors and therapists in implementing community-based health approaches was the amalgamation of the previously separate KwaZulu and Natal health departments. Many changes took place during this amalgamation, including a moratorium on the training of community health workers, which diminished the human resources available for CBR.[24]

Policy developments

The White Paper on the Transformation of the Health System in South Africa[25] was issued in 1997, however there was little recognition of CBR and rehabilitation in this document. Overall, health-service planning and provisioning overlooked rehabilitation as a component of PHC, putting persons with disabilities and their families at greater risk of experiencing the quadruple burden of disease.[26] The link between PHC and CBR was weakened. It was only when the initial burden of disease studies for South Africa were published in 2000[27] and linked with the global studies exploring disability adjusted life years (DALYs) that the link with rehabilitation was re-established,[28] and measurement of disability was seen to embrace both quantitative and qualitative elements.

The National Rehabilitation Policy[29] was adopted in 2000 and referred to CBR as a 'philosophy' rather than a strategy. This meant that the opportunity to prioritise CBR in a national rehabilitation policy failed because no resources could be allocated to a philosophy. In 2016, the Framework and Strategy for Disability and Rehabilitation Services (FSDR) was launched, stating that rehabilitation services at each level of care were to be comprehensive and based on the strategy of CBR.[30] The description of services to be provided at home and at community level included the following: "Utilise community rehabilitation workers and peer support counsellors within homes and communities wherever possible".[30] To date, there has been no provisioning for CBR services across the lifespan, and the FSDR lacks provincial implementation guidelines.

The White Paper on NHI[31] acknowledges rehabilitative care as part of the PHC continuum. However, one of the shortcomings of the White Paper is its lack of alignment with the FSDR[31] and with the provisions for rehabilitation within the UN CRPD. Further, review of progress in implementing NHI reveals that although indicators should relate to the span of services in universal health coverage,[32,33] there are currently no indicators relating to comprehensive rehabilitation services.[26]

South Africa has domesticated the UN CRPD through the White Paper on the Rights of Persons with Disabilities (WPRPD).[34] As articulated in the WPRPD and UN CRPD, CBR is not confined to the health sector, but speaks to the range of rights of persons with disabilities. The work of CBR Education and Training for Empowerment (CREATE) illustrates that CBR can be seen as a means by which to realise the rights of persons with disabilities.[35]

Advocacy alliances

During the period 1984-2020, two key advocacy partnerships shaped the development of CBR in South Africa.

1984-1995

The first partnership was the alliance between persons with disabilities, represented by Disabled People South Africa (DPSA) and rural therapists through the Rural Disability Action Group (RURACT). Other key role-players were civil society and government officials of rural 'homeland' governments. RURACT was launched in 1987, later hosting a series of CBR conferences and seminars bringing together (for the first time in South Africa) persons with disabilities and rehabilitation therapists around the country. Not only did this partnership promote the extension of the disability rights movement to rural areas,[36] it also helped to mobilise support for persons with disabilities and their families to be intimately involved in shaping and providing rehabilitation services together with rehabilitation professionals. For example, it enabled the development of the Mpumalanga CBR Disability Support Project, which commenced in 1998.

Despite complex power dynamics, RURACT challenged the three professional rehabilitation associations (Occupational Therapy Association of South Africa, Physiotherapy Association of South Africa, and South African Speech-Language-Hearing Association) on the importance of developing CBR in rural areas. Although additional pressure to act against Apartheid was exerted on these associations by their world federations, this did little to effect a shift to more equitable access to rehabilitation.

The strong partnership forged between RURACT and DPSA in 1987 held until 1995 when RURACT was disbanded.

2011 and ongoing

A second important advocacy partnership was facilitated by the Rural Health Advocacy Project (RHAP), which brought together key rural health providers, harnessing the collective bargaining power of rural doctors (RUDASA) and therapists (RuReSA).[37] This alliance took advocacy to a new level. Representation with the National Department of Health (NDoH) became possible, and resulted in compilation of the FSDR to which many RuReSA members gave input. However, the alliance did not include representation by the disability sector.

The alignment between RuDASA and RHAP, and the formation of RuReSA in 2011, assisted in ensuring a unified voice for rural health providers with regard to appropriate services. The creation and fostering of these powerful partnerships has enabled re-engagement with and advocacy for the training of MLCRWs, to provide human-resource capacity for disability and rehabilitation under NHI. To date, this has not progressed further towards a formal proposal and implementation.

From 2014, the RUDASA conferences have included therapists, clinical associates and rural nurses. These rural health conferences have provided a platform to promote the importance of MLCRWs, especially from 2016. A keynote speaker at the 2019 conference was a staff member of CREATE, herself a person with a disability and parent of a disabled child. At the conclusion of the 2019 conference, RuReSA drew up a resolution to advocate for the re-instatement of training of MLCRWs.

Understanding CBR

Historically, there have been various factors affecting how CBR was understood. For example, in Mpumalanga, the programme of Disabled People South Africa (DPSA) chose to focus on development, advocacy and activism, thereby shifting from rehabilitation to development and self-representation. In 2014/15, CREATE conducted national research into knowledge of CBR in South Africa, to ascertain whether there had been a shift in conceptualisation of CBR in line with international developments. Respondents included persons with disabilities, CBR facilitators, and government officials, although the majority described themselves as therapists. While 96.5% of respondents claimed to have been exposed to the concept of CBR, less than 20% indicated that they were up to date with developments in CBR.[38] This study found a general lack of understanding (including in government departments) regarding the scope of CBR and its potential as a strategy to achieve realisation of the rights of persons with disabilities.

Training of mid-level community rehabilitation workers

Various CBR training programmes for MLCRWs were initiated in South Africa from the early 1980s. While most of them focused on participation and empowerment of persons with disabilities in directing their own development, the programmes differed with regard to duration and structure, as well as with regard to how MLCRW roles were conceptualised. For example, in some cases community rehabilitation facilitators (CRFs) were equipped to provide basic rehabilitation services, while in other cases, CBR

consultants were trained to refer clients to services and resources rather than to provide services themselves.

Underpinning the training was recognition of the value of a community-level cadre of workers deployed to focus specifically on disability issues from the perspective of development. Gamiet and Rowe found that rehabilitation care workers (MLCRWs) trained in the Western Cape have strengthened PHC and CBR and contributed to promoting participation of persons with disabilities in inclusive development.[39] This differs from a community health worker whose primary focus is on acute conditions and treatment compliance.

Training was accompanied by advocacy for provisioning of posts. Indeed, some training programmes only accepted candidates on condition that they were guaranteed a post on completion of their qualification.

Recent literature indicates that MLCRWs require clinical, social, management, communication and cultural competency skills across the spectrum of the CBR matrix, especially in empowering persons with disabilities and facilitating community development. There has also been recognition of the need for development of critical reasoning, creativity and compassion.[40]

One of the greatest challenges with regard to the training of MLCRWs, however, was professional registration for this cadre of worker, mainly because they did not align with a single rehabilitation discipline. Further, there was little representation of rural disability issues by professional board representatives, and lack of understanding of CBR as the 'anchor' of a decentralised service aimed at reaching underserved areas. In 2006, the Health Professions Council of South Africa (HPCSA) ruled that the training could not continue. Instead, candidates were (re)directed to training and careers as Occupational Therapy Assistants (OTAs) or Occupational Therapy Technicians (OTTs), under the Occupational Therapy professional board. This training restricted their scope of community work as they were given hospital-based posts, with limited focus on community-based activities and no resources to support persons with disabilities at home.

Despite the 2006 ruling by the HPCSA, training for a community-level cadre of rehabilitation workers has continued. However, this has occurred in areas where funding has been available and leaders have emerged with a personal interest and commitment to furthering the agenda of CBR. Training is therefore fragmented and only happening in pockets, and there is still no agreement regarding the umbrella under which MLCRWs are to be registered.

Research done on CBR

An important advocacy element for CBR has been research into the situation of persons with disabilities (especially in rural and resource-poor environments). Over the past decade substantial research has been done on the unmet needs of persons with disabilities, especially in rural areas of South Africa.[41]

Research has also been conducted into the efficacy of CBR, documenting the fact that MLCRWs have the potential to improve access to health and rehabilitation services for persons with disabilities, thereby improving their independence and quality of life.[42] Binken and colleagues found that MLCRWs were able to provide a range of services for persons with disabilities at community level, including referrals, screening and assessment, and provision of assistive devices.[43] Their interventions contributed towards improved access to resources for persons with disabilities and increased interaction in communities. MLCRWs have also served to promote social participation of persons with disabilities, and contributed towards improved health and educational opportunities and the ability to access livelihoods. Further, MLCRWs have been documented as playing a leading role as catalysts for disability-inclusive youth development.[44]

Recommendations

Exploration of the history of CBR and MLCRWs in South Africa highlights the value of institutional memory and identifies lessons to strengthen CBR in response to the WHO's 'Rehabilitation 2030: A call for action'. These recommendations recognise the need to address systemic and political dynamics as well as the complexities of implementing global guidelines and national policies. The recommendations require engagement, monitoring, and reciprocal capacity development, which are essential to ensure equity and equal opportunities for and by persons with disabilities and to realise the vision of Rehab 2030.

Inclusion of CBR in a strategy for health care

It is recommended that rehabilitation in general and CBR in particular be foregrounded within PHC as a strategy to achieve the health rights of persons with disabilities. This requires consistency across policies, both within the Department of Health (national and provincial) and in relation to other government departments. Implementation should be overseen by an intersectoral structure such as the Office of the Rights of Persons with Disabilities in the Presidency. The NDoH needs to allocate resources not only for the development of rehabilitation services as part of its mandate under the SDGs, but also to invest in the training and deployment of MLCRWs within the workforce and referral chain of the health sector.

Advocacy for CBR

Given the challenges encountered to date, there is an urgent need for advocacy regarding the nature of CBR and its value as a means of achieving improved health and rights of persons with disabilities. Attention needs to be given to

extending the evidence base of CBR and opportunities for disseminating information and experience. Participation of government, academic institutions and civil society structures in shared platforms and (national and continental) CBR networks is important for the development of CBR within the country and the African context.

It is encouraging to see a growing focus on advocacy in training of occupational therapists[45] and this should be extended to other rehabilitation professionals, together with practical opportunities for them to collaborate with persons with disabilities, their families, and community structures.

Inclusion of persons with disabilities in CBR

Based on the maxim of the disability rights movement, namely "Nothing about us without us", it is critical that persons with disabilities be involved in planning, implementing, and evaluating CBR programmes. Structures and mechanisms to ensure their participation need to be in place from national to local level. For example, disability and rehabilitation forums at provincial level and disability forums at municipal level can serve this purpose. This is an urgent issue and it is recommended that it be resolved in an intersectoral round table forum, with the NDoH taking the lead in this process.

Re-activation of MLCRW training

It is recommended that training of MLCRWs be re-instituted at national level, towards realising the vision of Rehab 2030 for the most vulnerable people in South Africa. The National Qualifications Framework (NQF) level and accreditation of training should be determined nationally so that there is a consistent approach across training institutions. The NDoH needs to take the lead in resolving the issue of registration and designation of appropriate and sufficient posts for MLCRWs and their supervisors, together with career pathing and provision of continuing professional development.

Multi-sectoral partnerships and collaboration

By its nature, CBR is multi-sectoral and requires an approach that enables different sectors to collaborate to realise the rights of persons with disabilities. In working towards resolving the critical lack of human resources for rehabilitation arising from the quadruple burden of disease in South Africa, it is recommended that networks of stakeholders involved in CBR – including disabled persons' organisations (DPOs), non-governmental organisations (NGOs), institutions of higher learning, and various government departments – be strengthened towards sharing of available resources, research and expertise.

The restrictions imposed by the COVID-19 pandemic have led to a focus on social media and Facebook, spawning innovative ways of networking, including the Disability and Rehabilitation WhatsApp group. With over 80 members, the group includes persons with disabilities, service providers, government officials, and academics. This has been an extremely useful mechanism to exchange information and channel resources (particularly in the vernacular and for those in rural areas), including assistive devices, social relief, and psychosocial support. There is no hierarchy, no management structures, no meeting venue, and no personnel other than the person (one of the authors) who set it up.

In conclusion, achievement of the Rehab 2030 vision is only possible if stakeholders in the rehabilitation sector unite, particularly in resolving the acute need for human resources.

"Inaction will perpetuate an untenable status quo: first an increasing unmet need for rehabilitation … and second, a fragmented field that – despite its potential to address those needs – stops short of fulfilling that potential".[3]

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