Towards a Global Knowledge Creation Strategy: Learning From Community-Based Rehabilitation

By Bente van Oort, MSc and Djenana Jalovcic, EdD, MPA, MSc

Introduction

Over the last 40 years, community-based rehabilitation (CBR) has been used as a community development strategy that aims at improving the lives of persons with disabilities within their community, by working with and through local groups and institutions. This Perspective aims to shed light on the development of CBR across the world, emphasizing the strength of adaption and adoption of the framework globally, but also stressing the importance of aiming for more global knowledge creation in the field of rehabilitation.

The beginnings of CBR can be traced back to the 1978 Declaration of Alma-Ata, which set an ambitious and broad goal of Health for All through primary health care. Recognizing health inequalities and viewing health as a human right, the Declaration promoted the development of a sustainable, comprehensive primary healthcare system. Although the Declaration has failed to be implemented globally, it can be considered as an impetus for a wider use of a human-rights approach to health.[1] In addition, for the first time in history rehabilitation was included in primary healthcare. The Declaration of Alma-Ata called for primary healthcare to address the main health problems at the community level by providing "promotive, preventive, curative and rehabilitative services."[2]

CBR was initially launched by the World Health Organization (WHO) as a strategy to increase access to rehabilitation services for persons with disabilities in so-called low- and middle-income countries (LMICs).[3] WHO focused on the development of a training manual for people with disabilities in the community to provide CBR services.[4] Over the next four decades, CBR has evolved into a much broader and multisectoral approach to community-based inclusive development (CBID).[5] In 2010, the WHO published CBR Guidelines to provide guidance for the development and strengthening of CBR programs, promote community-based development inclusive of persons with disabilities, support stakeholders to meet their basic needs, and enhance the quality of life and facilitate

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empowerment of people with disabilities and their families.[6]

CBR Guidelines were developed as a result of a collaborative global effort of more than 180 individuals and representatives of almost 300 organizations mostly from LMICs.[2] They are built on the matrix representing CBR's key components including health, education, livelihood, social sectors, and empowerment. The CBR matrix reflects social determinants of health in the sense that it recognizes the non-medical aspects that influence the lives of people with disabilities. CBR Guidelines are informed by the UN Convention on the Rights of Persons with Disabilities (CRPD), a social model of disability, and the International Classification of Functioning, Disability and Health (ICF). They are reflective of social determinants of health and sustainable development goals.[7] Health was viewed broadly and holistically as influenced by physical, environmental, and personal interactions. In this way, healthcare professionals and researchers began to look beyond the bedside to society as a whole.

Over time, CBR and CBID have evolved and transformed to meet the needs of persons with disabilities in more than 90 countries. The diversity of CBR implementation models speaks to the strength and sustainability of a flexible global strategy that can be adopted, adapted, and altered to meet the specific needs of persons with disabilities in specific contexts. Conversely, diversity presents a challenge to CBR's development and understanding of its effectiveness across countries, fields, and disciplines — as every CBR approach is context-specific, making it hard to generalize its impact. The growing body of research on CBR has established that —despite its issues with cooperation between non-governmental organizations (NGOs) and local health workers, financing, legal disputes, and communication — CBR is a feasible and efficient way of providing guidance and assistance to persons with disabilities.[8-14] However, CBR is still considered "data rich and evidence poor."[15]

In this article, we discuss the differences in rehabilitation research and practices between high-income countries (HICs) and LMICs in relation to community-based rehabilitation. Pertaining to our discussion are the social and political forces that influence health and healthcare.

Understanding the Differences Between HICs and LMICs

Recently, an increasing number of researchers have addressed the ubiquitous and non-reflexive use of the terms 'LMICs' and 'HICs' as categories across disciplines and their attached preconceived assumptions.[16-17] Therefore, we find it important to address the terminology used in this article. While we recognize the debate and the contention this division creates, we deliberately chose to use these terms in this perspective piece, as this divide showcases the exact problem we aim to address. Too often, the situatedness of CBR practice is assumed to take place in the LMICs, and too little attention is paid to the spaces and political realities in which rehabilitation practices take place. In this perspective, we aim to showcase how understanding the difference and organizing mutual learning regarding rehabilitation approaches in LMICs and HICs can allow for the further improving of rehabilitation worldwide.

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Although CBR has been suggested globally as a strategy for rehabilitation, equalization of opportunities, poverty reduction, and inclusion of persons with disabilities within overall community development,[18] it was mostly implemented in LMICs. Consequently, most benefits, knowledge, practice, and research on CBR have been generated in and remained within these geographical areas. High-income countries (HICs) rarely seem to use the CBR approach for rehabilitation practices, relying mostly on highly specialized medical services.[19] Reasons for the paucity of CBR practices in HICs and its use in LMICs, may be caused by 4 interrelated factors: (1) Different knowledge systems; (2) Infrastructural differences; (3) Attitudinal barriers from researchers; and (4) A shift in the WHO's approach toward CBR.

1. Different knowledge systems. Historically in HICs, the medical model of disability was used in rehabilitation practices, which primarily focused on physical impairments in individuals that resulted in functional limitations.[20] Disability was not often contextualized —that is, considered without reference to social and environmental factors. This fact was in contrast with CBR principles, which embraced a rights-based approach and the social model of disability. While increasingly HICs adopt the social model of disability and the ICF model, which partially accounts for contextual factors, the main focus of rehabilitation remains on medical interventions to address individual physical improvements.[21] Moreover, while the ICF model identifies the needs and challenges of individuals by focusing on activities and participation, CBR expands upon this further by also considering community development, rehabilitation facilities, and the equalization of opportunities and social inclusion of persons with disabilities. While CBR focuses on five components: health, education, livelihood, social factors, and empowerment — representing a more holistic approach — the ICF maintains a narrower focus on biopsychosocial health.[22-23]

2. *Infrastructural differences.* The differences in health infrastructure, workforces, access to care, and financial resources, have resulted in different focal points in the rehabilitation practices in HICs and LMICs. For example, rehabilitation professionals in HICs often have access to more high-technology rehabilitation and assistive devices than practitioners in low-resource settings.[24] CBR was created to respond to the needs of persons with disabilities and their practitioners, and to find sustainable solutions in low-resource settings.[25] HICs focused on the development of new interventions.

3. *Attitudinal barriers from researchers.* HICs might use aspects of CBR, but do not call it CBR.[26-28] As CBR was created initially for use in non-Western countries, HICs — due to issues related to (post-)colonialism that reject other, non-western knowledge — may not feel compelled to CBR, suggesting it is only for those in low-resource settings as opposed to 'their' advanced rehabilitation centres.[29] Moreover, while "data rich – evidence poor" CBR calls for more methodologically-sound research. it also calls for HICs to examine views, values, understanding, and acceptance of different types of knowledge and data, as well as evidence in languages other than English. The fact that this is currently only done on a small scale leads one to question whether high-quality evidence is a privilege afforded to wealthy countries.[30] It is important to recognize forms

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of evidence and research, even when this does not comply with the research standards of academic journals in HICs. Balakrishna Venkatesh of CBR Global Network describes this point further when stating: "People with limited resources don't live for evidence, they live by supporting each other, building community resilience, mutual respect, interdependence."[31] Also, while in most cases, CBR research is driven and funded by HIC researchers, it is important to search for an equitable partnership in which the HIC's contribution is meaningful and useful for CBR stakeholders. This is especially important to avoid perpetuating colonial structures and authorship parasitism (meaning that research papers include no authors affiliated with the country in which the study took place).[32]

4. A shift in the WHO's approach toward CBR. Finally, CBR has been the mainstay of the WHO's rehabilitation approach since 1978, including the more recent WHO Global Disability Action Plan 2014-2021. One of the objectives in this plan stated the intention "to strengthen and extend rehabilitation, assistive technology, assistance and support services, and community-based rehabilitation."[33p16] However, CBR was notably absent from all WHO's initial Rehabilitation 2030 documents. Rehabilitation 2030 is an initiative that draws attention to the profound unmet need for rehabilitation globally, calling for rehabilitation to be an essential part of the health system and part of universal health coverage available for all.[34] Only after the efforts from CBR advocates, the WHO Executive Board proposed a resolution to urge the 76th World Health Assembly to include CBR strategy "to develop the community based rehabilitation strategy."[35-36] This showcases how CBR as a rehabilitation strategy is acknowledged only after the advocacy efforts of CBR experts around the world. For Rehabilitation 2030 to reach its lofty goals of rehabilitation, investment in CBR communities is crucial. We echo here again the words of Venktash: "You have to increase the knowledge and skills of people in the community, to provide care wherever they are. There is no universal health coverage without CBR. There's no other developed methodology available." [31]

Six Challenges and Learning Opportunities

The divergence between HICs and LMICs not only slows further development of CBR research, as there are few CBR case studies being conducted in HICs, but also hinders a global approach to knowledge creation in rehabilitation practice at the community level. If HICs and LMICs find themselves in need of mutually-exclusive approaches to rehabilitation, knowledge exchange in the global field of rehabilitation is hindered. The Rehabilitation 2030 initiative, a global approach to rehabilitation, had the potential to build on four decades of sustainable development of data-rich and knowledge-diverse CBR. Engaging in historical and contextual reflection may help to illuminate common challenges around the world, allowing for mutual learning and understanding — and ultimately may improve the lives of the one billion persons with disabilities globally. As a call for global knowledge-creation, six current challenges to rehabilitation practices worldwide are discussed in this article, to exemplify how knowledge from either LMICs or HICs may provide insights and solutions.

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1. PARTICIPATION OF PERSONS WITH DISABILITIES AND ATTENTION TO ALL ASPECTS OF LIFE

Increasing emphasis is placed on using a holistic approach to rehabilitation; however, many practitioners struggle with questions about how to organize or implement this approach in their daily practices. In most HICs, this entails a shift from a traditional focus on the improvement of mobility and physical independence toward a focus on the improvement of societal participation of persons with disabilities through mitigating environmental barriers.[37-38]

In contrast, since its start in the 1970s, CBR approaches acknowledge that a person's quality of life is determined by more than just physical abilities. Over the previous four decades, the participation of persons with disabilities remained at the core of many CBR projects. These projects have established a great deal of knowledge about the provision of education, vocational training, employment, and political participation as part of the rehabilitation process.[39] Moreover, many CBR projects focused on the competence development of persons with disabilities to address their specific needs and ensure equal opportunities and rights.[41-42] Additionally, other CBR projects helped persons with disabilities to become self-advocates.[43] This created a significant amount of expertise among persons with disabilities and a valuable body of knowledge that could be easily exchanged and contextualized globally.

2. ATTENTION TO FAMILY MEMBERS AND COMMUNITY

Living with a disability or participating in rehabilitation affects not only an individual but the people in their lives as well. While in HICs, family-centered rehabilitation programs are being further developed, their successful implementation is often challenging, as the health needs of family members and informal caregivers are not considered part of rehabilitation.[44] A CBR approach includes parents, neighbors, friends, teachers, employers, and community members throughout the rehabilitation process. However, challenges related to the sustainability of such involvement are experienced.[45-47] A mutual exchange of lessons learned between persons using CBR or rehabilitation services, their families and friends, and practitioners regarding family-centered rehabilitation, may not only empower persons with disabilities and those around them but contribute to the creation of a more disability-inclusive society.[48]

3. SUSTAINABILITY

One of the major strengths and challenges of CBR is sustainability. CBR has been successfully sustained over 40 years and implemented in 90 countries through flexibility of approaches, adaptability to local contexts, collaboration with diverse stakeholders, reliance on available resources, and participation of persons with disabilities. The availability of human resources, training, monitoring and evaluation, collaboration, commitment, and financing is crucial for the further development of CBR programs.[49] In HICs, most rehabilitation services are part of mainstream care practices, and are more likely to collaborate horizontally with NGOs, and have more access to international lobbying.[50-51] Lysack and Kaufert compared CBR in LMICs to a rehabilitation practice for individuals living in North America with respect to sustainability practices and concluded that these approaches have a lot to learn from each other.[52] Moreover, Alheresh and Cash have argued for academic-community partnership — in their

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case, between community members in Jordan and graduate students from the United States — to produce outcomes for research and interprofessional cooperation in a sustainable, cost-effective way.[53] Comparing strategies, sharing data and experiences, and exchanging knowledge on a global level can provide many new insights on sustainability.

4. HOME AND COMMUNITY-BASED REHABILITATION SERVICES

In most western countries, centre-based rehabilitation programs are considered the mainstream rehabilitation service. However, a number of randomized controlled trials studying home-based rehabilitation programs are introduced in HICs to increase access and participation.[54-56] Particularly in light of the recent COVID-19 crisis, in which many rehabilitation centre-based practices were suspended, alternative models like home-based rehabilitation are increasingly being studied.[57] In rural areas, home- and community-based rehabilitation has been the norm due to limited resources and infrastructure.[58-59] Therefore, studies about the effectiveness of these practices may provide valuable insights into the opportunities and challenges of home- and community-based rehabilitation.[60]

5. HUMAN RIGHTS AND SOCIETAL ATTITUDES

The Convention on the Rights of Persons with Disabilities (CRPD) is a human rights instrument that promotes human dignity and emphasizes the importance of full participation in society for individuals with a disability. Many signatory states are currently struggling with the process of ratifying and implementing this Convention.[61] The CRPD is, however, integrated with the CBR guidelines. The CBR guidelines provide guidance on how to develop and strengthen CBR programs, support communities in addressing basic needs, enhance quality of life, and promote the rights and empowerment of persons with disabilities and their families.[6] Evaluation studies on the implementation and usefulness of these guidelines could provide valuable information about the impact of the CRPD on rehabilitation practice.

6. COMMUNITY-BASED HEALTH AND PAYMENT MODELS

The economic dimensions of healthcare have been a source of controversy and innovation throughout the world. These dimensions can also pose barriers to equitable access to rehabilitation services at the community level — both in LMICs and HICs. While CBR programs often struggle with reducing the dependency on human, financial, and material resources from external sources, rehabilitation practices in certain HICs also face problems with access due to private insurance regulations and the impact of significant out-of-pocket costs. Universal health coverage (UHC) and the inclusion of rehabilitation services as a part of the UHC package have the potential to address this problem in both high- and low-resource settings.[62-63] For example, in Bosnia-Herzegovina, one of the poorest countries in Europe, CBR services are provided through a network of over 60 CBR centres located within primary healthcare facilities. The network was built after the war in the 1990s through development projects that mainstreamed CBR into primary healthcare. The CBR network has made available and accessible services that

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could improve functional independence, participation, and community integration of persons with disabilities throughout the country.[64] CBR services are part of the basic health insurance package, making them affordable to those in need regardless of their financial situation.[65-66]

On the other hand, the Canadian example illustrates that the exclusion of many outpatient rehabilitation services from UHC leads to health disparities. This model limits accessibility of rehabilitation services for Canadians who do not have private insurance and cannot afford the associated out-of-pocket payments.[67] Aiming to ensure that all people have access to fundamental health services, when and where they need them, and without financial hardship, is a universal challenge and a good example of how global collaboration can encourage developing a more equitable approach to rehabilitation.

Conclusion

In this article, the authors highlighted the central tenets of community-based rehabilitation, outlined the needs of community members, and suggested opportunities for national collaboration to integrate knowledge between countries regardless of income categorization. Through highlighting opportunities for collaborative learning, information exchange, and knowledge co-creation surrounding the current challenges to rehabilitation service provision worldwide, we call on researchers, practitioners, and advocates to bridge existing gaps, challenge biases, and seek collaborative learning opportunities. It is only through a more unified approach that we will drastically improve rehabilitation services for and with all persons with disabilities and their communities across the globe.

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About the Author

Bente van Oort, MSc obtained her research master's degree in Global Health in 2022 and is currently working with health policy. Earlier she worked with the Dutch Health Research Institute on rehabilitation research in the Netherlands and with a Dutch NGO aiming to improve the societal participation of young people with a disability. With an open vision, eagerness to learn, and social commitment, Bente is passionate about translating theory into practice and policy into impact.

Djenana Jalovcic, EdD, MPA, MSc is an Associate Professor and Coordinator of the Master in Healthy Ageing and Rehabilitation program at Western Norway University of Applied Sciences. She has over three decades of experience as an educator, researcher, and community development practitioner in the field of global health, inclusive development, and community-based rehabilitation. She integrates humanities into interprofessional education of health professionals by using a critical lens to examine rehabilitation practices, bring forward multiple marginalized voices and experiences, and address health inequities within diverse cultural, social, political, and historical contexts.

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