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COMMENTARY

Strengthening Rehabilitation for People with Disabilities

A Human Rights Approach as the Essential Next Step to Accelerating Global Progress

ABSTRACT

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Since 2008, 152 countries have ratified the United Nations Convention on the Rights of People with Disabilities (CRPD), making it one of the most widely accepted human rights treaties of this century. In emphasizing universal and equal access to health care for all people with disabilities, the CRPD recognizes rehabilitation as a key component of the right to health and puts specific obligations on governments with respect to rehabilitation services planning and programming.[1] Having timely access to a properly resourced and well-functioning system of care and being able to attend an individualized rehabilitation program are basic human entitlements and are fundamental to enable people with disabilities to achieve their full potential—to find employment, to go to school, to care for their families, to contribute to their communities and ultimately build coherent societies.

Arguably, international human rights law is an important parameter in the design and implementation of health policies at the country level as it sets out specific requirements and standards that derive from the State's moral responsibilities toward its citizens.[2] Hence, ratification of international human rights treaties is a precondition for all people to be able to claim their rights and seek appropriate remedy in case of violation. Implementation of human rights is less probable without ratification[3] but can also fail after it.[4] The transposition of international instruments into national law, constitutional or other, is an essential step for the implementation of human rights. This is especially true for the CRPD, which holds governments responsible to "adopt all appropriate legislative measures for the implementation of the rights recognized in the present Convention,"[5] including the right to health.

Insufficient incorporation of international human rights law in domestic legislation may limit the ability of people with disabling conditions to claim

full access to rehabilitation and other age-, sex-, or condition-specific services and results in the deprivation of care supports crucial for people with disabilities' health and well-being. In addition, given that agenda setting is essentially a competition for attention and resources, underrecognition of rehabilitation as a human rights issue hinders the efforts of professional and disability advocacy organizations to generate political and community concern about systemic barriers to access to rehabilitation services. Thus, there is an urgent need to address rehabilitation from the perspective of international law and highlight its significance as a human rights issue in global health fora.

The World Health Organization Disability Action Plan: A Transformative Moment for Rehabilitation

Fortunately, opportunities for change are emerging, most promisingly through an international effort headed by the World Health Organization that addresses access to quality rehabilitation in its Global Disability Action Plan.[6] The action plan provides a road map and a menu of policy options for United Nations agencies, Member States, and other stakeholders to take coordinated action at all levels, local to global, to attain specific targets for strengthening and extending rehabilitation. The main focus of this plan is on removing barriers to access to health care. It suggests targeted investments in improving systems governance for equitable and responsive service provision, capacity building, and rehabilitation services organization. The plan is also aimed at motivating and supporting governments in their implementation activities to fulfill human rights responsibilities with respect to rehabilitation. The plan recognizes the pivotal role of research in this process and calls upon all stakeholders to promote research at the intersection of health and human rights to achieve universal health coverage—a practical but comprehensive expression of the right to health.[7] As global institutions and policy leaders advocate for new models of health care delivery[8] and research as essential for realizing universal health coverage,[9] we need to better understand what human rights law, and particularly the CRPD, entails for the rehabilitation sector. The effort and process to reengineer rehabilitation care systems and improve access to rehabilitation and assistive health technologies must be framed in human rights law terms.

In this regard, it is worth mentioning the efforts of the International Society for Physical and Rehabilitation Medicine (ISPRM) to implement the recommendations of the World Report on Disability through research and policy advocacy in different world regions.[10] In this context, the ISPRM is convening the 9th World Congress in Berlin, Germany, on June 19–23, 2015 with the main topic *Joining Efforts towards the Implementation of the WHO Disability Action Plan 2014–2021* "*Better Health for All People with Disabilities*" (www.isprm2015.org). The congress represents an opportunity to take stock of implemented initiatives and set out a strategy for translating current political opportunities into concrete scientific and public health impact. In a recently published editorial, ISPRM leaders discuss the implications of the aforementioned plan for physical and rehabilitation medicine and provide thoughtful suggestions for the ISPRM to achieve a new strategic vision for rehabilitation research and advocacy action.[11] However, the human rights dimensions of rehabilitation service planning and programming have not been treated in much detail.

A Human Rights–Based Approach for Rehabilitation Service Planning and Programming

There are compelling reasons to argue for a strong focus on human rights aspects of rehabilitation as essential for making progress. Experts in the field draw our attention to distinctive features of human rights in rehabilitation care and highlight the need to initiate processes for the application of human rights norms and standards in clinical practice and service delivery.[12] International human rights law offers a useful framework for initiating such processes of change in rehabilitation service organization. Specifically, the CRPD requires governments to "…better *organize, strengthen and extend* comprehensive habilitation and rehabilitation programmes particularly in the area of health…,"[5] which implies strategic action toward strengthening health system in its entirety, part of which is the subsystem of rehabilitation care. But what exactly does this mean and where should the rehabilitation sector focus its efforts to fulfil this duty?

This tripartite duty of states to "organize, strengthen, and extend" prompts attention to distinct dimensions of rehabilitation service planning, development, and provision (Table 1). First of all, a T1 rights-based approach to organize, strengthen, and extend rehabilitation services requires the formulation of new policy objectives that reflect the values of the CRPD and foster processes to reengineer rehabilitation delivery systems. Such objectives should

TABLE 1 The tripartite duty of states to better organize, strengthen, and extend rehabilitation services and programs in the area of health

Tripartite Duty Under the CRPD	Action Required	Facets of Service Planning and Programming	Synopsis of the Obligation
Better organize rehabilitation services and programs	Reengineer service delivery systems	Availability	• Ensure a comprehensive range of rehabilitation services and products is available, appropriate to the needs of the target population (comprehensiveness) • Ensure sufficient density of rehabilitation professionals in accordance with the epidemiologic profile of the population
		Accessibility	• Make services directly and permanently accessible to the target population ensuring specifically: physical accessibility of facilities and equipment; information accessibility; economic accessibility (affordability) of services, products, and technologies; service proximity and the provision of reasonable accommodation when appropriate
		Acceptability	• Provide culturally appropriate services based on principles of patient-centered care (patient centeredness)
		Quality	• Ensure services are organized and provided when needed in accordance with acceptable standards of professional practice and without causing any harm (timeliness, effectiveness, safety)
		Coordination	• Develop rehabilitation programs that integrate the efforts of various providers
		Continuity	• Model service delivery in a way that provides people with disabilities with continuity of care across health care settings and levels and over the life cycle • Ensure the development and implementation of rehabilitation plans that are tailored to the individual with a disability after a multidisciplinary assessment of his or her health, social, and financial needs and strengths
		Efficiency	• Adopt and implement optimal models of rehabilitation service management to achieve the dimensions described above with minimum resource wastage (disease or care management programs)
Extend rehabilitation services and programs		Coverage	• Incorporate rehabilitation and provision of assistive devices in national universal health coverage plans
		Decentralization	• Decentralize rehabilitation services to reduce geographic disparities in access • Adopt where appropriate alternative modes of rehabilitation service provision such as telerehabilitation or mobile rehabilitation outreach programs
		Integration	• Integrate rehabilitation medicine as a core component inestablished collaborative care networks designed to meet the needs of people with multiple and/or complex disabling conditions (integrated care pathways)
Strengthen rehabilitation services and programs	Revitalize policies	Governance and leadership	• Build and strengthen democratic governance processes and capacities of rehabilitation institutions and providers • Promote all of government and sector-wide approaches to address rehabilitation needs

(continued on next page)

TABLE 1 *(Continued)*

Tripartite Duty Under the CRPD	Action Required	Facets of Service Planning and Programming	Synopsis of the Obligation
		International assistance and cooperation	• Promote stakeholders dialogues at national and international level to identify priority issues and devise implementation strategies to address those through resource mobilization and knowledge transfer
		Participation	• Strengthen the genuine, active, and meaningful participation of people with disabilities in the conduct of health affairs relevant to rehabilitation • Empower people with disabilities to advocate for their own health and rehabilitation needs through health literacy
		Monitoring and accountability	• Invest in the collection of accurate and comparable data on rehabilitation services including research evidence • Develop participatory monitoring mechanisms and indicators to allow transparent reporting on performance and progress achieved
	Rethink values and outcomes in clinical practice and research	Research, training, and education	• Invest in research on rehabilitation including assistive health technologies • Promote the integration of disability into medical curriculum and other training programs for health professionals

be included in national rehabilitation care strategic plans designed to meet needs, address obstacles, and set benchmarks to ensure progress.[13] Broadly, a rights-based rehabilitation plan should focus on:

- Reengineering service delivery systems to meet needs and rights of people with functional limitations (organize and extend)
- Revitalizing policies and rethinking values and outcomes in clinical practice, education, and research (strengthen).

Specifically, in the process of implementing the abovementioned tripartite duty, rehabilitation service planning and programming should be primarily concerned with ensuring the availability, accessibility, affordability, acceptability, and quality of services and programs especially in countries with high prevalence of disability.[1] Regarding quality, policy makers must make every effort to ensure that services are organized and provided when needed in accordance with acceptable standards of professional practice and without causing any harm (timeliness, effectiveness, and safety). This will require integration of rehabilitation into the national health system and the development of evidence-based guidelines and clinical protocols for a range of health conditions. Policy makers and service planners should also consider the adoption and implementation of evidence-informed models of service delivery that ensure a high degree of care coordination across types of providers and levels of provision and a more positive experience across the continuum of care. In addition, rehabilitation programs must be negotiated between providers, payers, and purchasers to allow resources to be combined in the most efficient way.

Extending rehabilitation services will ensure that people's needs are properly covered, especially the needs of high-cost patients who have multiple or complex disabilities and require intense support. This may be realized by making rehabilitation an integral component of national universal health coverage plans and ensuring an appropriate level of decentralization in an effort to reduce geographic disparities in access to rehabilitation. Lawmakers and service managers have a variety of innovative and potentially cost-effective models from which to choose to achieve maximum coverage such as telerehabilitation[14] or mobile outreach clinics.[15]

In clinical practice, a rights-based approach for strengthening rehabilitation requires professionals to move away from a curative approach to rehabilitation for improving health and functioning and consider more comprehensive and holistic models of

care provision, informed by human rights principles and standards.[16] These models recognize the inherent dignity and worth of every person and the right of individuals, including children and people with mental disabilities, to make informed choices across the rehabilitation continuum[17] and challenge professionals to promote alternative means of optimizing functioning such as self-management and peer support. It also requires rehabilitation educators and academics to reassess existing clinically orientated educational programs and consider rights-focused training strategies that aim to highlight and strengthen the role of practitioners as facilitators of social participation of people with disabilities through the implementation of human rights in patient care.[18] Finally, rehabilitation researchers, clinicians, and therapists may need to expand the rigid boundaries of clinical performance measurement, as drawn by measures of evidence-based medicine, considering additional metrics that target the preferences and desired service outcomes of the person with a disability bearing in mind that optimal functioning of an individual can only be achieved in the least restrictive physical, social, and economic environment.

Strengthening rehabilitation services will ensure effective provision of rehabilitation. Effective provision presumes a well-functioning, properly regulated, and resourced health care system.[19] In developed nations, strengthening rehabilitation may be a matter of improving organizational aspects of service delivery such as efficiency, coordination, and quality of care, but in limited resourced settings and in areas affected by conflict, establishing a well-functioning system to address the rehabilitative needs of people with disabilities depends largely on political factors such as a country's political commitment and attention to the needs of people with disabling conditions[20] or the effective distribution of official development assistance for health according to disease burden and needs.[21,22] The success of efforts to strengthen rehabilitation will also depend on the existence of knowledge transfer mechanisms, the adequacy of health infrastructures including information systems, and good governance. Therefore, health system strengthening cannot be understood solely in terms of organizational or clinical improvement interventions; it demands progressive steps to strengthen the invisible facets of service planning and development. This entails acting on strengthening governance and leadership capacities of institutions, promoting international development cooperation and assistance in rehabilitation and assistive health technologies, investing in rehabilitation service data, and ensuring citizens' participation in the conduct of health affairs and public accountability, many of which are missing components in existing health systems study frameworks.[23]

The process of implementing the rehabilitation-related provisions contained in the CRPD must proceed alongside efforts to build evidence for policy in all aspects described above, which are key obligations of States under the treaty. This may require professional and advocacy organizations to prioritize specific measures to fulfill their role as change agents in global rehabilitation. Indicative measures include

1. Facilitating stakeholders dialogues within the frame of international development cooperation to identify needs and priorities for knowledge transfer and exchange[24]
2. Assisting governments in developing national rehabilitation plans
3. Promoting global and national advocacy campaigns for serious investments in rehabilitation services research and engaging in resource mobilization activities
4. Promoting the integration of disability into medical curriculum and training programs of other health professionals
5. Assisting in the development of evidence-based programmatic tools such as monitoring guidelines with indicators to track progress with the implementation of the CRPD.

Rehabilitation care is fundamental to health and human dignity and is a basic human right. Past initiatives have not proven successful in improving access to rehabilitation and the problem is reaching critical proportions especially in low-income countries. The current state of affairs represents a major failure that needs to be corrected. The international rehabilitation community needs to mobilize resources and knowledge to promote access to quality rehabilitation services for all. In this respect, a position statement and a clear commitment at the forthcoming ISPRM congress in promulgating an agenda for research and collective action on the human rights aspects of rehabilitation outlined above can serve as the first but critical step toward accelerating global progress.

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