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SPECIAL COMMUNICATION

Health-Related Rehabilitation and Human Rights: Analyzing States' Obligations Under the United Nations Convention on the Rights of Persons with Disabilities

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Abstract

Globally, disability represents a major challenge for health systems and contributes to the rising demand for rehabilitation care. An extensive body of evidence testifies to the barriers that people with disabilities confront in accessing rehabilitation services and to the enormous impact this has on their lives. The international legal dimension of rehabilitation is underexplored, although access to rehabilitation is a human right enshrined in numerous legal documents, specifically the Convention on the Rights of Persons with Disabilities. However, to date, no study has analyzed the implications of the Convention for Rehabilitation Policy and Organization. This article clarifies states' obligations with respect to health-related rehabilitation for persons with disabilities under the Convention. These obligations relate to the provision of rehabilitation but extend across several key human right commitment areas such as equality and nondiscrimination; progressive realization; international cooperation; participation in policymaking processes; the accessibility, availability, acceptability, and quality of rehabilitation services; privacy and confidentiality; and informed decision making and accountability. To support effective implementation of the Convention, governments need to focus their efforts on all these areas and devise appropriate measures to monitor compliance with human rights principles and standards in rehabilitation policy, service delivery, and organization. This article lays the foundations for a rights-based approach to rehabilitation and offers a framework that may assist in the evaluation of national rehabilitation strategies and the identification of gaps in the implementation of the Convention.

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It is estimated that roughly 15% of the world population experiences some form of disability,[1] with 110 to 190 million people having severe or extreme difficulties in functioning.[2] The 2010 Global Burden of Disease study highlighted that musculoskeletal disorders account for 6.8% of the world's burden of health conditions in terms of disability-adjusted life-years and that chronic low back pain is the leading cause of years lived with disability.[3] Neurological disorders account for an estimated 3.4% of the total disability-adjusted life-years and are the cause of nearly 43 million years lived with disability.[4] These numbers likely underestimate the true burden of disability because they do not include long-term health conditions that may be associated with comorbidities such as stroke, diabetes, and chronic obstructive pulmonary disease. Moreover, the trends suggest that these numbers will rise because of demographic aging and the shift of the global epidemiological pattern toward noncommunicable diseases, mainly as a result of unhealthy lifestyle and the aging process.[5] This increase in disability prevalence, along with a range of barriers that people with disabilities confront in accessing health care, has fueled vigorous political debates that have brought the issue of disability to the forefront of the global health debate[6,7] about how to meet the rising demand for general and specialist care, especially rehabilitation.[8,9]

Today, there is an overall consensus that rehabilitation is an important resource for individuals with disabilities and their

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families and contributes directly to their well-being as well as the social and economic development of the entire community. It is also true that the contemporary notion of specialized care cannot be understood solely in terms of medical interventions. Arguably, the provision of comprehensive rehabilitation is an enormously complex task because rehabilitation goals are not impairment driven but are centered around the individual's health and social needs. Thus, an array of targeted rehabilitative services across multiple sectors may be deemed appropriate to cover the needs of the disabled person, ranging from health care interventions to psychosocial support and counseling, vocational training, return-to-work programs, and environmental adaptations and modifications. The delivery of these offerings is regulated differently in different contexts, and each type of rehabilitation service has its own specifications. For the vast majority of people with disabilities, rehabilitation becomes available through the mechanisms of community-based rehabilitation, an inclusive development strategy that aims to foster participation of people with disabilities in all spheres of civic, social, and economic life and to empower the entire community through the application of tailored and context specific social and economic measures.[10,11]

However, in the realm of health, rehabilitation is understood as a strategy aiming to optimize physical and mental capacities and functioning of people who experience or are likely to experience disability.[12] Health-related rehabilitation is delivered along a continuum of care ranging from hospital care to rehabilitation in primary care and community settings and includes measures to enable a person to achieve and maintain optimal functioning in interaction with his or her environment.[1] Several studies have demonstrated the effectiveness of a broad range of rehabilitation measures in improving health outcomes for a wide range of chronic disabling conditions,[13-15] as well as the cost-effectiveness of rehabilitation interventions in various settings and situations.[16,17] In addition, from the perspective of service users, rehabilitation contributes to positive perceptions of illness[18] and has been seen as a turning point in the lives of people with disabilities.[19]

Despite the evident benefits of rehabilitation, health systems globally are failing to respond adequately to the rehabilitation needs of persons with disabilities. An extensive body of evidence documented in the World Report on Disability[1] testifies to the significant number of physical, attitudinal, and institutional barriers that people with disabilities confront in accessing rehabilitation services and the enormous impact these barriers have on the individual, society, and the economy. Examples of such systemic barriers include inadequate policies and standards, negative attitudes, lack of service provision, inadequate funding, lack of physical accessibility to buildings and examination rooms, inappropriate technologies and formats for information and communication, and lack of participation in decisions that directly affect their lives.

These problems are not new, and several policy responses have been offered at various levels and jurisdictions. At the global level, human rights law has established and expanded standards for the health of people with disabilities that include standards for rehabilitation services. The human right identified in the International Covenant of Economic, Social and Cultural Rights—namely, "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health"—has been authoritatively interpreted to encompass rehabilitation services for people with disabilities.[20] In 2008, the United Nations Convention on the Rights of Persons with Disabilities (CRPD)[21] entered into force, and to date, 158 countries have explicitly reaffirmed in Article 25 "the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability."(p18) This right is further expanded in Article 26 to require state parties to "take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life."(p19) Article 26 stipulates further that this requires states to "… organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health …"(p19)

Despite this overall global commitment, expressed in both the CRPD and the World Report on Disability, concrete actions to improve access to medical rehabilitation for persons with disabilities are inadequate and substantial challenges remain, not only in low-resource countries of the world[22,23] but also in medium- and high-resource countries.[24-26] The lack of evidence-informed policy guidance and the absence of monitoring mechanisms to assess progress in improving access to rehabilitation are among the main causes of this phenomenon. This lack is partially explained by the recognized gap in research on rehabilitation for people with disabilities,[27] including particular issues relevant to the implementation of human rights.[28] In fact, a recent systematic review of the literature in the area of health and human rights over the last decade has highlighted the small proportion of studies that have examined issues relevant to health-related rights of persons with disabilities.[29] Finally, the absence of high-quality evaluative research in rehabilitation further impedes progress in improving health systems' response to the needs of people with disabilities.[30]

Although much of the existing research in this area has contributed to our understanding of rehabilitation service delivery through the lens of medical ethics and human rights,[31-35] it has ignored the significant issue of accountability and the need to monitor human rights implementation. Researchers have seldom considered in detail the responsibilities of states concerning rehabilitation with a view to inform the development of rights-based policies and robust monitoring mechanisms to ensure compliance with the CRPD. From a public health perspective, concrete guidance is needed for the design of responsive policies and rehabilitation programs that enhance individual well-being as well as for selecting optimal models of care provision to improve the efficiency and economic productivity of the system. But most importantly, guidance on legal obligations is critical to promote the full realization of the rights of persons with disabilities in the rehabilitation sector.

Given the dearth of research information, the overall objective of this study was to define a broad human rights–based framework for rehabilitation to support effective monitoring and implementation of the CRPD at different levels and functions of health and health-related systems. Specifically, the aim here was to identify in detail the range of legal obligations of states that have ratified the CRPD in relation to rehabilitation services as specified in Articles 25 and 26 of the CRPD. Methodologically, the analysis of the human rights provisions will be carried out in accordance with treaty interpretation methods described in the Vienna Convention on the Law of the Treaties.[36] In addition to the legal sources, academic literature from the field of global health and rehabilitation has been used to illustrate the linkages between human rights and rehabilitation practice and organization.

List of abbreviations:

CRPD Convention on the Rights of Persons with Disabilities