

Health related rehabilitation and human rights: Analyzing States' obligations under the 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. **Key words:** Rehabilitation, Human rights, Persons with Disabilities, Jurisprudence, Delivery of Healthcare, Convention on the Rights of Persons with Disabilities - CRPD

1. Introduction

It is estimated that roughly 15% of the world population experiences some form of disability¹ with 110–190 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 as they do not include long term health conditions that may be associated with co-morbidities such as stroke, diabetes and chronic obstructive pulmonary disease. Moreover, the trends suggest that these numbers will rise due to demographic ageing and the shift of the global epidemiological pattern towards non communicable diseases, mainly as a result of unhealthy lifestyle and the ageing process.⁵ This increase in disability prevalence, along with a range of barriers 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 families and contributes directly to their wellbeing 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, 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 is delivered in the community through the mechanisms of Community Based Rehabilitation which aims to foster participation of disabled people in all spheres of civic, social and economic life and empower the entire community through the application of inclusive and human rights based development strategies.^{10,11}

In the realm of health however, 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 their 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 a variety of settings and situations.^{16,17} Additionally, from the perspective of service users, rehabilitation contributes to positive perceptions of illness¹⁸ 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 Disability¹ 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 144 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”. This right is further expanded in Article 26 to require States 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.” 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...”.

Despite this overall global commitment, expressed both in 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 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

While 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 rights³¹⁻³⁵, 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 wellbeing 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 is to define a broad human rights based framework supporting effective and comprehensive implementation of the rehabilitation strategy and the CRPD at different levels and functions of health and health related systems. Specifically, the aim here is to identify in

detail the range of legal obligations of States who have ratified the CRPD in relation to rehabilitation services as specified in Articles 25 and 26 of the Convention. Methodologically, this legal 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.

Before considering health related rehabilitation further in the particular context of human rights law, however, some clarifications are required concerning some of the definitions adopted and the conceptual approach taken in this analysis.

2. Preliminary clarifications

2.1. Why a focus on rehabilitation

While human rights issues are increasingly discussed in areas of health such as reproductive health,³⁷ HIV/AIDS³⁸ and mental health,³⁹ the rehabilitation sector has lagged behind. Rehabilitation is frequently seen as a relatively unimportant, secondary service for people who have impairments. Rehabilitation needs are still sidelined in health policy programming and the availability of specialized rehabilitation services, including assistive devices,⁴⁰ is far from adequate. A clear understanding of the human rights approach to rehabilitation will help disability advocates and health professionals raise rehabilitation higher on the crowded global health policy agenda. This is especially important since rehabilitation services are instrumental in creating and preserving the ability of people with disabilities to enjoy many of the most important dimensions of human life, including participation in education, employment and community life.

Nearly 80% of people with disabilities live in low resourced countries⁴¹ with poor access to health and rehabilitation,⁴² further impeding freedom and choices.⁴³ In many instances, political and economic arrangements leave people with limited capacity to exercise their fundamental human rights, including the right to health and rehabilitation⁴⁴ and resourcing is lacking for a well-functioning rehabilitation sector. Bringing State obligations with regard to rehabilitation to the forefront will help the global disability community to mobilize resources for rehabilitation and countries to rationalize their health budgets and prioritize investment in this sector.

Finally, disability is an important health issue.⁴⁵ Although some accounts of disability insist that social structures and inequities are largely responsible for the widespread disadvantages people with disabilities experience⁴⁶ and that this fact alone explains poorer health outcomes,⁴⁷ a human rights approach to disability would be deficient if it did not take fully into account the underlying health condition and its impact on the experience of disability. People with chronic disabling health conditions and other impairments have greater health care needs, both in general and needs that are specific to their primary or secondary conditions. Prominent among those needs are those for good quality and accessible rehabilitation services.

2.2. Health related rehabilitation: in search of a rights – based description

Traditionally, rehabilitation has been associated with an approach to disability in which it is viewed as a biological defect of the individual. Because of this, during the drafting of the CRPD, advocates for people with disabilities were reluctant to identify a ‘right to rehabilitation’ thinking this would further entrench this approach to disability.⁴⁸ In practice, however, rehabilitation care has never been delivered from this purely medical perspective since both rehabilitation theory and the organization of rehabilitation services have themselves been largely influenced by progressive disability theories,⁴⁹ health care ethics,³⁵ institutional arrangements, health systems structures and processes, but more importantly by the attitudes and views of persons with disabilities, the clients of rehabilitation services.^{50,51} Gzil et al. note that rehabilitation as a science and practice field has managed to find its way away from a ‘curative paradigm’ to one that sees impairments as a natural part of the human diversity, acknowledging the role that both health conditions and the environment play in the construction of disability.⁵² The authors refer to McPherson who states that “presuppositions about the ‘normality of functioning’ no longer play a role in rehabilitation theory because rehabilitation does not require a preconceived standard of potential for typical function to establish treatment goals.”⁵³

Rehabilitation thus goes far beyond the medical approach to health care to embrace the complete lived experience of people with disabilities, addressing as well the concerns of public health policy. Perhaps the most comprehensive statement of this expanded view of the scope of rehabilitation has been articulated by Meyer et al. who define rehabilitation as a

“health strategy which applies and integrates approaches that build on and strengthen the resources of the person....that enhance health related quality of

life in partnership between person and service provider and in appreciation of a person's perception on his or her position in life over the course of health condition ...with the goal to enable persons experiencing or likely to experience disability to achieve and maintain optimal functioning”⁵⁴

This conception of rehabilitation is fully consistent with fundamental human right principles like respect for the inherent dignity of the person, participation, independence and autonomy, all of which are key outcomes of rehabilitation and not external goals adopted on an ad-hoc basis. This inclusive understanding of the scope of rehabilitation creates the space for disability theorists, human rights lawyers, development practitioners and rehabilitation professionals to come closer and share a common human rights based approach to the structure, organization and delivery of rehabilitation care.

3. The legal basis to claim the right to access rehabilitation for persons with disabilities in relation to health

In the last 40 years, countries and multilateral agencies have acknowledged the importance of rehabilitation and affirmed their commitment to strengthen and promote rehabilitation for persons with and without disabilities in various declarations and resolutions. There are numerous human rights instruments, some of which address issues pertaining specifically to disabled persons while others view rehabilitation more broadly as a public health and social development issue. The most important of these international instruments are summarized in Table 1.

[Insert Table 1 here]

The CRPD is now the primary legal basis for the recognition of rehabilitation as a component of the right to health. Specifically, Article 25 requires States to uphold “*the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability*” and “*ensure access for persons with disabilities to **health services** that are gender sensitive, including **health related rehabilitation**”.*

The CRPD drafters, on the insistence of the World Health Organization towards the final stages of the negotiation process, introduced the term ‘health related rehabilitation’⁵⁵ as a response to the concerns of those who did not wish to entrench a ‘right to (re)habilitation’ under Article 26.

In the recent case of *H.M v. Sweden*⁵⁶ the CRPD Committee has examined health related rehabilitation from a wider perspective and offered a way to view rehabilitation as a fundamental and indispensable precondition for preservation of health and enjoyment of equality, autonomy, independence and participation. This is an important step towards a human rights understanding of rehabilitation. According to the Committee, by denying the complainant permission to build an in-home hydrotherapy pool, Sweden had violated not only the right to access health related rehabilitation without discrimination under Article 25, but also its obligation to consider the individual's needs and strengths when providing rehabilitation services as articulated in Article 26 of the Convention.

The influence of the CRPD on the formulation of domestic rehabilitation policy is also reflected in a recent decision of the Constitutional court of Belarus.⁵⁷ The court in considering the constitutionality of a new law creating an obligation to the State to provide treatment and rehabilitation to people with disabilities, has considered that the delivery of rehabilitation depends both on State bodies and the individual's willingness and readiness to perform the scheduled rehabilitation measures and that participation in rehabilitation should always be voluntary as provided in Article 26 of the CRPD. Therefore the Court decided the constitutionality of the specific provision of the law which allowed the renunciation from a proposed rehabilitation program after providing sufficient justification since it creates the space for people to realize their right to autonomy and self-determination and creates the means for them to withdraw their consent to rehabilitation.

4. States' obligations under the CRPD

Article 4 sets out the 'General Obligations' of the CRPD and provides interpretative context in the sense that "the obligations prescribed will attach themselves to the Article under consideration".⁵⁸ Under standard rule of human rights interpretation, this entails that States have three kinds of obligations generated by each right: First, States are responsible not themselves to violate human rights directly; they are also responsible to protect their citizens from having their rights violated by other non-State actors; and lastly, they are obliged to ensure that all of the preconditions that enable people to realize their rights are in place. This is standardly expressed as the tripartite obligation to *respect, protect* and *fulfill rights*.⁵⁹

While this tripartite scheme may be useful as part of a comprehensive analytic framework to describe key elements of States' responsibilities, it leaves room for overly broad interpretations of the content of measures that States need to adopt in order to

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realize human rights to the fullest extent possible. Classification of duties and typologies of human rights obligations are of little practical value unless they take into account the complexity of human rights implementation and the concrete reality of the uniqueness of each and every human right.⁶⁰ This is especially true for the CRPD, the innovative character of which lies in the fact that it transcends the conventional divides of human rights (positive *v.* negative, civil and political *v.* economic and social, individual *v.* collective) thus challenging existing categorizations of States' obligations.⁶¹

In the area of health related human rights, an analytic framework has been proposed by the United Nations Special Rapporteur on the right to the highest attainable standard of physical and mental health that can more successfully unpack the meaning of the right to health for the purpose of identifying States' obligations.³⁹ This framework, which has been initially described and applied in the context of disability,⁶² is widely adopted and is a useful approach to specifying rehabilitation related rights and the corresponding State duties. Building upon and complementing the legal arguments of this analytic framework, this article proposes a framework for rehabilitation service planning and evaluation which illustrates the full range of the key responsibilities of States under the CRPD (Figure 1). The legal obligations of States can be summarized under the following headings:

[Insert Figure 1 here]

4.1. Non-discrimination, equality and reasonable accommodation in provision of rehabilitation

Discrimination is both a cause and consequence of disability and violates the inherent dignity and worth of the person, and as such non-discrimination and equality are critical components of a human rights based approach to health related rehabilitation.⁶³ The CRPD defines discrimination in Article 2 as “any distinction, exclusion or restriction on the basis of disability which has the purpose of impairing or nullifying the recognition, enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms....” remarking that this includes the denial of reasonable accommodation.⁶⁴ This feature of States' obligations calls primarily for its rights protective function.

Article 25(f) and (e) require States to prevent discriminatory denial of health care and services, including rehabilitation, and prohibit discrimination in health insurance. This is particularly important for people with complex disabilities who require more intensive support (Preamble (j)). An example of where this might be violated is the

so-called ‘improvement standard’ used in the United States in its Medicare program to determine the medical necessity for skilled nursing or therapy services and has resulted in many people with chronic disabling conditions being denied rehabilitation or having their therapy discontinued.⁶⁵ In their exercise of its obligation of non-discrimination, signatories to the Convention are urged under Article 4 (1)(b) to modify or abolish laws, regulations, customs or practices that constitute discrimination or have the power to produce a discriminatory effect which may adversely affect people’s access to health and rehabilitation services.

Finally, stigma - which refers to ignorance, prejudice and discrimination - ⁶⁶ may impede access to health services thus widening population health inequalities.⁶⁷ By virtue of Article 25, the CRPD proscribes any discrimination to access to health care including access to rehabilitation services and programs putting an obligation on States to combat and eliminate stigma as a barrier to access to rehabilitation services.

4.2. Progressive realization and international responsibilities in the provision of rehabilitation

Human rights law acknowledges that the full realization of economic, social and cultural rights will always depend on a country’s financial condition, so that the implementation of some provisions may be so costly that they can only be achieved progressively as additional resources become available.⁶⁸ The doctrine of progressive realization provides the flexibility that some countries, especially low and medium resource countries, may require in order to live up to their obligations.⁶⁹ The CRPD recognizes the reality of resource constraint in Article 4(2) and requires States to make the most efficient use of resources – human, technological, scientific and financial – available to ensure full enjoyment of human rights. In particular, this means that States have, *inter alia*, an obligation to engage in international development cooperation (Article 32) in order to (i) facilitate and support the exchange and sharing of information, experiences, training programs and best practices in rehabilitation and care organization; (ii) facilitate cooperation in rehabilitation research and access to technical knowledge; and (iii) provide financial and technical assistance, including knowledge transfer of accessible and assistive technologies.

4.3. Active involvement and participation in rehabilitation service planning

It is increasingly recognized that people’s involvement in the processes that affect their health and lives is extremely important from a human rights perspective.⁷⁰ The right to participate individually and collectively in order to have the opportunity to influence the decisions that directly affect them is also a prominent feature of a

people-centred approach to health.⁷¹ From a right to health perspective it has been argued that “effective provision of health services can only be assured if people’s participation is secured by the State”.⁷²

In the CRPD, participation of people with disabilities in decision making processes is both a general interpretative principle and a direct State obligation. The Preamble states that persons with disabilities “should have the opportunity to be actively involved in decision making processes about policies and programs, including those concerning them” and Article 3(c) includes “full and effective participation and inclusion” among the eight governing principles of the treaty. A more detailed description of State obligations in relation to participation is provided in Article 4(3), according to which States have an obligation to closely consult with and actively involve persons with disabilities in the development and implementation of legislation and policies for the implementation of the CRPD, as well as in other decision making processes that deal with issues that concern them.

Crucially, rehabilitation and the arrangements for its provision are relevant to persons with disabilities and their participation in service and policy design is essential since they have their own perception of their rehabilitation needs and desired outcomes that may differ from the views of professionals.⁷³ Research evidence has shown that user involvement in the design of assistive devices delivery models predicts better outcomes of satisfaction, device utilization and quality of life.⁷⁴ The CRPD requires States to establish institutional mechanisms and a framework to ensure real, meaningful and genuine participation of people with disabilities during the entire policy cycle.^{75,76} States are also expected to mainstream rehabilitation in national health strategic plans and the principle of participation expands this obligation to create the conditions that facilitate people to participate in the development, implementation and monitoring of the interventions described in those strategic policy documents.^{77,78}

4.4. Availability, accessibility, acceptability and quality of rehabilitation services, products and facilities

The use of human rights standards in the provision of health related rehabilitation for persons with disabilities prompts attention to the issues of the availability, accessibility, acceptability and quality of such services and programs (AAAQ).⁷⁹ These terms are spread throughout the CRPD and have concrete and direct implications for rehabilitation:

Availability: Governments must make rehabilitation services and programs

available to persons with disabilities under Article 26 (1)(b); 26 (3) also require States to “promote the availability, knowledge and use of assistive devices and technologies as they relate to habilitation and rehabilitation.” Along the same lines, Article 20(b) requests States to make mobility aids, devices and assistive technologies available as a means to ensure personal mobility and independence of people with disabilities and Article 4(1)(g) requires States to promote availability by prioritizing the most economical solutions. Finally, Article 19 (b) requires states to make rehabilitation and other community based health programs available so as to prevent isolation from the community.

Accessibility: Article 9 makes accessibility a central focus of human rights. The chapeau of that article mandates governments to take all appropriate measures to ensure that persons with disabilities enjoy, on an equal basis with others, access to facilities and services open or provided to the public, including public rehabilitation facilities, programs and services. In this regard States parties are obliged to adopt, promulgate and monitor national accessibility standards.⁸⁰ Article 9(1)(a) specifically makes it an obligation to identify and remove obstacles to medical facilities and Article 26(1)(b) and 25(c) point to the further requirement of service proximity, which is intrinsic to the concept of accessibility⁸¹ and requires rehabilitation services to be offered as close as possible to people’s own homes, even in rural areas.

Accessibility also implies that rehabilitation services and related equipment be affordable. (Article 25(a)). Evidence from high income countries shows that people with disabilities are faced with higher health care costs than their non-disabled peers⁸² with the vast majority paying out of pocket for assistive devices and supportive equipment.⁸³ Moreover, people with lower household income are less likely to obtain the devices they need, which undermines their health and participation.⁸⁴ In less developed parts of the world in particular, States may need to increase their capacity to produce and distribute high quality-low cost assistive devices and to develop a national list of essential devices covered by national insurance schemes.⁸⁵⁻⁸⁷ Finally Article 28(2) and its general provision for an adequate standard of living, implies that rehabilitation services must be appropriate and affordable.

Acceptability: Health services in general must be attentive to cultural variations.⁸⁸ Rehabilitation is no exception, so its services and programs, including counselling, peer support, and assistive technologies, must be provided in a manner that is culturally acceptable.⁸⁹ In fulfilling their commitment under Article 25, States must provide health related rehabilitation services in a manner that is also gender sensitive and suitable for

their particular need^{90,91}, as well as age specific. Article 25(b) points to the latter by making explicit mention of children and older persons as recipients of services designed to minimize and prevent further disabilities.

Quality: Article 25(a) stipulates that States provide persons with disabilities with the same “range, quality and standard of care” as it does to everyone. Quality of care is a matter both of the quality of the procedures, tests and services received, -- so that the benefit of care outweighs any risks – and that care is provided in a humane and culturally appropriate manner with the participation of the intended beneficiary.⁹² From a disability perspective however quality of care is closely linked with providers’ knowledge of disabling conditions and effective communication between provider and patient.⁹³

All healthcare facilities, commodities and services must, as a matter of human rights, be scientifically and medically appropriate and of good quality. This includes appropriately trained staff to provide good quality care responsive to people’s needs,⁷² which is linked to the need for training on human rights issues themselves: Article 4(1)(i) obligates States “to promote the training of professionals and staff working with people with disabilities on the rights recognized in the Convention as to better provide the assistance and services guaranteed by those rights”. This is further reinforced in Article 25(d) which mandates that States raise awareness among health professionals as to the need to provide care to people with disabilities with the same quality of service as they do to others, respecting their inherent dignity, autonomy and other the need for informed consent. Article 20(c) also requires State parties to provide practical training in mobility skills to specialist staff working with persons with mobility restrictions. Article 26(2) places an obligation on States “to promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation”.

Relevant to the quality of rehabilitation care is the requirement that habilitation and rehabilitation plans and treatments be based on a multidisciplinary assessment of the individual status of the person -- Article 26(1)(a). Assessment in rehabilitation is the first and most important step in the treatment process and needs to be holistic to allow successful goal planning, identification of appropriate interventions and evaluation of outcomes achieved.⁹⁴ In organizing rehabilitation services and programs States must ensure that the rehabilitation plan offered is based on an interprofessional, multidisciplinary assessment of the person’s needs and strengths.

4.5. Informed decision making in provision of rehabilitation services

Showing respect for the inherent dignity and individual autonomy of the person, including the freedom to make his or her own choices is expressed in Article 3(a). The concept of autonomy – the perceived capacity to control and make personal decisions⁹⁵ – is central to client based rehabilitation.⁹⁶ This is reflected in Article 26(b) that mandates States to organize rehabilitation services “in such a way that these services and programmes...are voluntary...”. According to Article 12, in general, and specifically in the case of rehabilitation services in Article 25(d), this means that service providers are obliged to support persons with disabilities in making decisions about rehabilitation by providing relevant information in accessible format.^{97,98} Relevant information includes a description of a patient’s health and functioning status, description of assessments and interventions, benefits and risks of available rehabilitation options and any additional information that will assist in making an informed choice.⁹⁹ Nonconsensual rehabilitation with doubtful therapeutic outcomes is not only contrary to Article 12 and 26, it is also in violation with Article 17 that states that “every person has a right to respect for his or her physical and mental integrity”.

4.6. Privacy and confidentiality in provision of rehabilitation services and information

The collection and sharing of personal information about individuals receiving rehabilitation care requires consideration of the duty of confidentiality and data protection. Article 22(2) expressly stipulates that States shall “...protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others”. Consequently States need to take all appropriate measures, including by means of legislation, to protect the privacy of personal information. For their part, professionals are expected to act in accordance with existing national laws and ethical standards to avoid unwarranted disclosures of information that have been provided with the expectation of confidentiality.¹⁰⁰

4.7. Accountability in the provision of rehabilitation services and information

Accountability refers to the obligation of governments and its organs to account for its decisions and actions by accepting responsibility for them, disclosing the results in a transparent manner, and be subject to some form of enforceable sanction if they do not.¹⁰¹ Accountability is recognized as critical to the realization of the right to health and is a core component of good governance for health.^{102,103} The right to health contains an entitlement, especially for those who historically have suffered violations of their rights, to access effective mechanisms of accountability and request appropriate remedies.¹⁰⁴

The CRPD poses obligations on States regarding all three dimensions of accountability: Article 33(1) assigns to States the responsibility to “designate one or more focal points within government” for issues pertaining to the implementation of the Convention and facilitate action in different levels and sectors of the government by establish a coordination mechanism. Article 33(2) obliges States to establish a “framework, including one or more independent mechanisms, as appropriate to promote, protect, and monitor implementation of the Convention”. This provision stresses the obligation of States to monitor the implementation of the CRPD. In doing so, under Article 31, States have an obligation to collect all relevant information, including statistical and research data, to help them assess their progress in achieving the objectives of the treaty and to disseminate this information in accessible formats.

5. Conclusion

This paper explores the legal basis and range of State obligations with respect to the right to rehabilitation found in human rights law, most particularly the CRPD, and suggests a human rights based framework for rehabilitation service planning and evaluation.

Human rights are expressions of moral values with legal implications on States as the principal duty bearers. Human rights are indivisible, interrelated, interdependent and indispensable and therefore cannot be achieved in isolation. As such, the right to access to and benefit from rehabilitation is closely linked to and dependent upon the realization of other rights such as the right to equality and non-discrimination, the right to self-determination, the right to privacy and the right to informed consent. These rights call upon fundamental values such as participation and inclusion, respect for diversity, individual autonomy and independence.

This review shows that health related rehabilitation is inextricably linked with the right to health and health care. In international human rights law, rehabilitation is a means to an end. Article 26 does not, nor could it, provide a guarantee to the final outcomes and goals of rehabilitation -- optimal functioning -- but only to access to rehabilitation services and programs. It is this that “*enables people 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*”.

A rights based approach to rehabilitation calls for the participatory design and promotion of practical solutions to deal effectively with the long standing

misapprehensions around the *modus operandi* of rehabilitation. Notably, in their concluding observations on Australia's progress report, the CRPD Committee stated that a purely medical approach to rehabilitation cannot be said to be based on human rights;⁷⁶ and later in the case of China, the Committee recommended the government institute a rights based approach to rehabilitation that respects autonomy and the will and preferences of the person.¹⁰⁵

The results of the present legal analysis confirm the results of social science research in the field of health service evaluation. The proposed framework which derives from an objective analysis and interpretation of human rights law is broadly consistent with a previously published generic framework which has been developed through a participatory process and used for the evaluation of rehabilitation policies in specific contexts.³³ The framework presented in Figure 1 adds to previous research in that it places a particular emphasis on the obligations of States with a view to monitor compliance with human rights standards in rehabilitation and identifies areas of responsibilities under the CRPD which are not covered by previously published evaluation models.¹⁰⁶ One of these obligations is the obligation of progressive realization which requires States to take immediate steps in implementing their commitments and engage in international cooperation to realize disabled peoples' rights progressively.

There is a growing recognition that global and national health policies should be attentive to legal norms and deeper understanding of the concrete elements of each and every human right is critical to the application of human rights standards in practice.¹⁰⁷ Knowledge of States' responsibilities under international human rights law and particularly of human rights aspects in rehabilitation policy design and organization can contribute to the efforts of governments to re-engineer rehabilitation service delivery in order to improve the responsiveness and reduce the disadvantage people with disabilities experience when interacting with the rehabilitation system and ultimately facilitate the full and equal enjoyment of other health related human rights.

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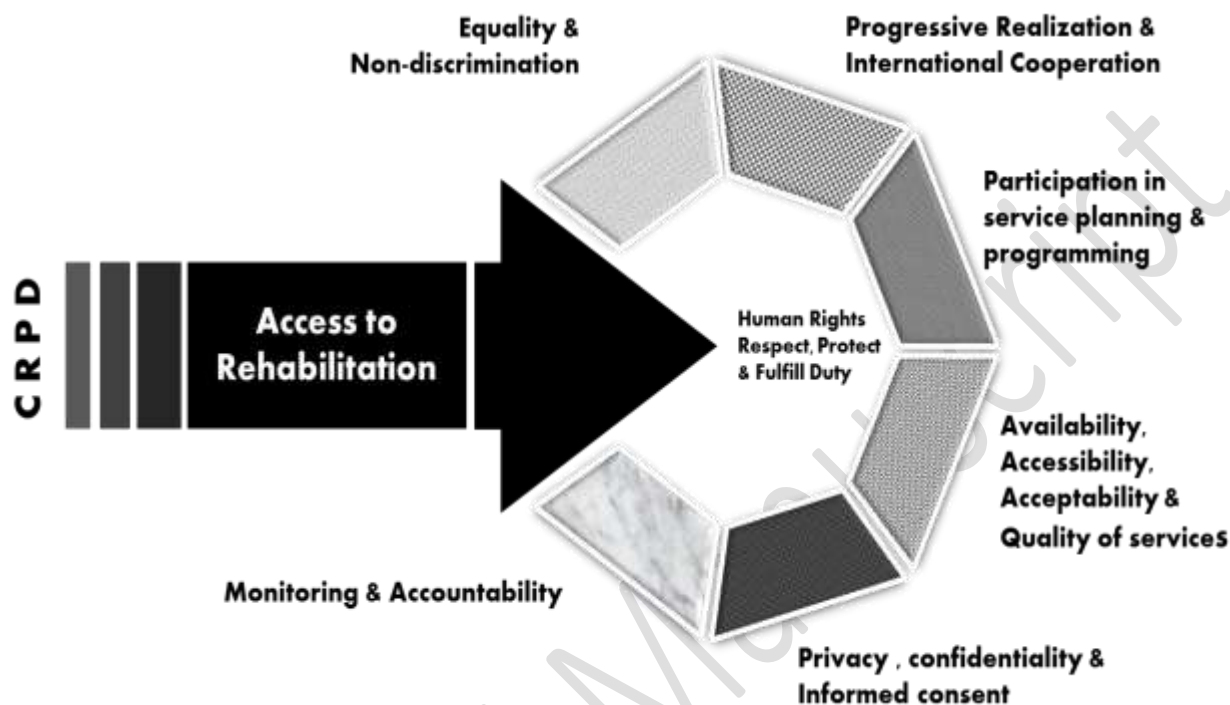
Accepted Manuscript

TABLE 1 . International legal and political instruments referring to health related rehabilitation

Instrument	Date of adoption	Disability specific	Reference to Rehabilitation
<i>Non binding</i>			
Declaration on Social Progress and Development	Proclaimed by General Assembly resolution 2542 (XXIV) of 11 December 1969	No	Article 19, par(d)
Declaration on the Rights of Mentally Retarded Persons	Proclaimed by General Assembly Resolution 2856 (XXVI) of 20 December 1971	Yes	Paragraph 2
Declaration on the Rights of the Disabled Persons	Proclaimed by General Assembly Resolution 3447 (XXX) of 9 December 1975	Yes	Paragraph 6
Declaration of Alma-Ata	Adopted by the International Conference on Primary Health Care on 12 September 1978	No	Paragraph VII
World Programme of Action concerning Disabled Persons	Adopted by General Assembly Resolution 37/52 on 3 December 1982	Yes	Paragraphs/ 1, 5, 9, 11, 15-21, 33, 36, 39, 40, 43, 47, 56, 57, 77-80, 82, 84, 90, 97,100, 118, 131, 143, 144, 153,156, 172, 174, 176-179, 192
Tallinn Guidelines for Action on Human Resources Development in the Field of Disability	Adopted by General Assembly Resolution 44/70 of 15 March 1990	Yes	Paragraphs 4 and 5 Paragraphs 3,30,31,50 (Annex)

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities	Adopted by General Assembly Resolution 48/96 of 20 December 1993	Yes	Introduction – par 23 Rule 1 (par 8), Rule 3, Rule 4 (par 5)
Copenhagen Declaration and Programme of Action	Report of the World Summit for Social Development, held in Copenhagen 6-12 March 1995, United Nations, New York 1995	No	Commitment 6 par (n) and (x)
<i>Binding</i>			
International Covenant on Economic, Social and Cultural Rights (ICESCR)	Adopted by General Assembly Resolution 2200A (XXI) of 16 December 1966	No	CESCR General Comment 5 CESCR General Comment12
Convention on the Rights of the Child (CRC)	Adopted by General Assembly Resolution 44/25 of 20 November 1989	No	Art 23, par(3) and (4) Art 24, par(1) General Comment 9
Convention on the Rights of Persons with Disabilities (CRPD)	Adopted by General Assembly Resolution 61/106 on 13 December 2006	Yes	Article 4 par1(f, g, h ,i) Article 16 par(4), Art 22 par(2), Article 25, Article 26

FIGURE 1. Human rights based framework for rehabilitation service planning and evaluation



Note: The Convention on the Rights of Persons with Disabilities (CRPD) is the primary legal basis for people with disabilities to claim their right to access rehabilitation. The tripartite duty of States to respect, protect and fulfill human rights is a central feature of a rights based approach to rehabilitation. The six interlocking components of the framework highlight the indivisibility of human rights and explicate the content of this fundamental obligation. Each trapezoidal shape refers to a key area of the responsibilities of the States. In human rights terms, governments have the following obligations: (i) to ensure equal access to and non-discriminatory provision of rehabilitation, (ii) to engage in international cooperation to achieve progressively the realization of the right to access and benefit from rehabilitation, (iii) to ensure the genuine and active participation in the planning and programming of rehabilitation services of the intended beneficiaries, (iv) to ensure the accessibility, availability, acceptability and quality of rehabilitation services and programs, (v) to protect the privacy and confidentiality of rehabilitation information and ensure the individual's informed consent, (vi) to account for their decisions and actions and establish participatory mechanisms to monitor compliance with human rights standards in rehabilitation service organization.