THE WORLD REPORT ON DISABILITY – IMPLICATIONS, PERSPECTIVES AND OPPORTUNITIES FOR PHYSICAL AND REHABILITATION MEDICINE (PRM)

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On June 9th 2011 the WHO World Report on Disability (WRD), called for by the World Health Assembly (WHA), was launched at the United Nations headquarters in New York. The WRD displays what has come to be known as the integrative model of functioning and disability as expressed in the International Classification of Functioning, Disability and Health (ICF). The present paper summarizes the representation of the role of rehabilitation in the WRD. It in particular highlights implications, perspectives and opportunities for Physical and Rehabilitation Medicine (PRM) and the International Society of Physical and Rehabilitation Medicine (ISPRM). The WRD acknowledges the genuine role of PRM and its contribution to enhancing a person’s functioning and participation in life. Challenges lie in the delivery of rehabilitation services in underserved parts of the world, ranging from the provision of timely, cost efficient and effective treatment, and the involvement of people with disability, family and care givers in the decision making process. In the present paper it is concluded that these challenges and the implementation of the WRD’s recommendations call upon multiple actors including ISPRM and for national rehabilitation strategies that can coordinate scarce resources effectively, especially in times of crisis such as disaster relief efforts.

Key words: disability; World Health Organization; physical and rehabilitation medicine; rehabilitation medicine; international agencies/organization & administration; information dissemination; health policy; disaster relief planning; World Report on Disability

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INTRODUCTION

On June 9th 2011 the WHO World Report on Disability (WRD) (1), the WRD constitutes the most visible and potentially influential global health policy reference work for rehabilitation for the next decade. It was called for by the World Health Assembly resolution on Disability, including prevention, management and rehabilitation (4) also requesting member states to strengthen national rehabilitation services in line with the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities and the CRPD (5).

The WRD was produced in collaboration with many stakeholders including the International Society of Physical and Rehabilitation Medicine (ISPRM), the international body of Physical and Rehabilitation Medicine (PRM) in official relation with the World Health Organization (WHO) (6, 7).

The WRD displays what has come to be known as the paradigm shift away from solely seeing disability as an impact of a health condition toward a new integrative model of functioning and disability that understands disability in light of a health condition in interaction with the environment and personal factors (8–11).

The present paper summarizes the representation of the role of rehabilitation in the WRD. It will in particular highlight implications, perspectives and opportunities for PRM as set out by the Report itself and as evaluated by the authors. Conclusions will be drawn for the discipline in general, and more particularly for the role of ISPRM.

THE WORLD REPORT ON DISABILITY – AN OVERVIEW

Before we turn to discussing the representation of rehabilitation and PRM in particular in the rehabilitation chapter of the WRD, it is helpful to gain a broad overview of the rest of the Report and the underlying definition of disability.

After a general introduction to the conceptual foundations, the WRD portrays a global picture of disability in terms of basic prevalence data of disability, trends in health conditions associated with disability, basic demographics introducing children and the aging population as important subpopulations, and economic indicators, including poverty, service needs, and direct and indirect costs of disability. The WDR then turns its attention to the basic service areas of general health care, rehabilitation and assistance and support, before moving on to describing major life areas of people with disabilities. Enabling environments are
broadly understood as those living situations in which the impact of impairments are moderated, or even eliminated, by features of the person’s surroundings. The WRD concludes with the two major areas of participation: education and employment.

In its definition of disability, the WRD leaves behind the restrictive view of the medical dimension of disability by making clear that the medical and the social model are not dichotomous or mutually exclusive. It argues that disability is a complex, multidimensional concept, fundamentally dynamic in nature that engages both intrinsic features of human physiology and functioning and features of the physical and human-built, social and attitudinal environment. The WRD thereby seeks a balance by arguing on one hand that, whatever the underlying mechanism that creates it might be, impairment is essential to disability – and hence that disability is at some level intrinsically a health issue. On the other, the lived experience of disability is presented here as profoundly mediated, altered, or in some cases, completely constructed, by the physical, social and attitudinal context in which the person lives and carries out her life. It is this essential balance that is fundamental to both the concept and practice of rehabilitation. As we will now see the WRD acknowledges the central role of rehabilitation with all its facets emphasizing the capacity of rehabilitation to eliminate potential barriers to unrestricted participation in everyday life.

REHABILITATION MEDICINE IN THE WORLD REPORT ON DISABILITY

The WRD bases its description of rehabilitation on the fundamental human right to rehabilitation as expressed in Article 26, Habilitation and Rehabilitation, of the UN Convention on the Rights of Persons with Disabilities (CRPD). This Article calls for “appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life” (2). In light of this commitment, the WRD further calls on countries “to organize, strengthen, and extend comprehensive rehabilitation services and programs, which should begin as early as possible, based on multidisciplinary assessment of individual needs and strengths, and including the provision of assistive devices and technologies”. In doing so the WRD clearly states which major change agents it seeks to mandate with its policy and systems recommendations.

Definition of rehabilitation

The WRD describes disability as a problem people with health conditions experience in interaction with their environment. The WRD consistently highlights rehabilitation as an essential strategy to enable people with disabilities to participate in education, the labor market, and civic life (1), stating that rehabilitation needs to provide a wide range of measures that targets all aspects of functioning as described in the ICF (body functions and structures, activities and participation, environmental factors, and personal factors) from the improvement of functions to measures for the promotion of participation and inclusion (12, 13). Recent papers describing rehabilitation as a health strategy to address these needs have also used the ICF as a conceptual framework to describe all aspects of rehabilitation to meet these needs (9, 11, 13, 14).

Rehabilitation measures focus on:

- prevention of the loss of function;
- slowing the rate of loss of function;
- improvement or restoration of function;
- compensation for lost function;
- maintenance of current function.

In order to achieve these goals, the WRD stresses that rehabilitation must always be voluntary and that people with disabilities have to be included into all aspects of decision-making in the rehabilitation process and that furthermore, rehabilitation requires team-integrated action (1, 15–20). The WRD distinguishes between the following categories of rehabilitation measures:

- Rehabilitation Medicine;
- Therapy;
- Assistive Technologies.

The WRD gives examples of what such a team-based approach in rehabilitation can look like and describes the role of rehabilitation medicine and its specialties as being “concerned with improving functioning through the diagnosis and treatment of health conditions, reducing impairments, and preventing or treating complications”.

Turning to the rehabilitation settings, the WRD underlines that rehabilitation must be provided in acute care hospitals (mainly rehabilitation medicine and therapy) as well as in follow-up medical rehabilitation (all three categories) (p. 101). Within this context the WRD describes the broad spectrum of such follow-up settings, from hospital to multi-professional practices. For long-term rehabilitation the spectrum of settings is also wide, from primary health care centers to home-care services.

The WRD states that “rehabilitation medicine has shown positive outcomes, for example, in improving joint and limb function, pain management, wound healing, and psychosocial well-being” (p. 100), but underscores that some rehabilitation needs have gone unmet and identifies barriers to rehabilitation (p. 102).

Needs and unmet needs

Data on rehabilitation services, type and quality and estimates of needs and unmet needs are not readily available, nor are they standardized because of conflicting perceptions of the nature of disability. A clearer overview of rehabilitation needs can not only prevent health deteriorations and decrease in quality of life in persons with disabilities but can also prevent broader negative societal outcomes such as financial implications on the family and community level (p. 102).

From what data is available rehabilitation service needs and unmet needs can be shown. National studies in Africa have for example revealed:

- large gaps in the provision of medical rehabilitation;
- gender inequalities in access to assistive devices.

Surveys of physical rehabilitation medicine in Europe found:

- a general lack of access to rehabilitation in primary, secondary, tertiary, and community health care settings;
- regional and socioeconomic inequalities in access.
In a study in China a particularly high need for assistive devices and therapy was found. Surveys in the United States show high levels of unmet needs for assistive technologies caused by funding problems.

Actions to overcome barriers to rehabilitation service delivery
Based on this description of needs and unmet needs, the WRD provides a description of concrete actions that can help overcome barriers to rehabilitation service provision (p. 103). These include:

- reforming policies, laws, and delivery systems, including development or revision of national rehabilitation plans;
- developing funding mechanisms to address barriers related to financing of rehabilitation;
- increasing human resources for rehabilitation, including training and retention of rehabilitation personnel;
- expanding and decentralizing service delivery;
- increasing the use and affordability of technology and assistive devices;
- expanding research programs, including improving information and access to good practice guidelines.

Looking at these action items in more detail will make it possible to more clearly see the implications for PRM and its role in breaking down barriers.

Reforming policies, laws, and delivery systems (p. 104). The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities survey found that in the 42% of countries that responded rehabilitation policies were not adopted, in 50% of countries legislation on rehabilitation for people with disabilities was not passed, and in 40% of countries rehabilitation programmes were not established. Even in countries with good legislation and related policies on rehabilitation the implementation has lagged. Among the systemic barriers identified were: a lack of strategic planning, lack of resources and health infrastructure, lack of agency responsible to administer, coordinate, and monitor services, inadequate health information systems and communication strategies, too complex referral systems, and absence of engagement with people with disabilities. National rehabilitation plans and improved intersectoral collaboration are called for.

Developing funding mechanism for rehabilitation (p. 106). Costs of rehabilitation can be a barrier for people with disabilities both in high-income and in low-income countries. These might be due to problems and barriers to work and employment. The lack of financial resources can be a barrier in accessing assistive technologies. Recommended actions include the reallocation or redistribution of resources, to cooperate internationally, to include rehabilitation services in foreign aid for humanitarian crises (including disaster), to combine public and private financing, to target poor people with disabilities, and to evaluate coverage of health insurance including criteria for equitable access.

Increasing human resources for rehabilitation (p. 108). Challenges include inadequate information about the rehabilitation workforce, including the absence of uniform standard to describe it and discrepancies in the availability of rehabilitation experts between rural areas and cities and the complete lack of experts in many low and medium resourced countries. It is necessary to expand education and training in rehabilitation, to train existing health-care personnel in rehabilitation, to build training capacity, and to take action in recruitment and retaining rehabilitation personnel. Changes to the curriculum content should incorporate knowledge of human rights aspects to rehabilitation, use the ICF as a common language across rehabilitation professions to enhance communication between rehabilitation partners, and enhance context relevance of rehabilitation including community level interventions.

Expanding and decentralizing service delivery (p. 114). As rehabilitation services are often located in urban centres, many people with disabilities from rural areas find it difficult, because of the financial burden and inaccessible transportation, to take advantage of these services. Ineffective referral systems may as well be a major barrier, especially in cases where a person with disabilities has complex rehabilitation needs. Coordination of rehabilitation service delivery includes needs to improve and expand availability of coordinated multidisciplinary rehabilitation under one roof for effectiveness and efficiency. Community-delivered rehabilitation interventions are an important part of the continuum of rehabilitation services. In particular for low and medium resourced settings, Community Based Rehabilitation (CBR) complemented with secondary rehabilitation services provide timely service delivery. This includes identification of people with impairments and the facilitation of referrals, delivery of simple therapeutic strategies through rehabilitation workers, or taught to individuals with disabilities or family members, provision of individual or group-based educational, psychological, and emotional support services for persons with disabilities and their families, and the involvement of the community in the management of rehabilitation problems.

Increasing the use and affordability of technology (p. 117). Appropriate rehabilitation technology can enable people with disabilities to participate in all life areas. These include mobility aids, communication technology and many other kinds of assistive devices. Increasing their available on the market can be achieved by lowering costs by mass production or lowering tax rates for these products. Assistive technology needs to suit the environment, be suitable for the user, and services should include adequate follow-up to ensure safe and efficient use. Tele-rehabilitation specifically can enhance the capacity and accessibility of rehabilitation measures. This includes the use of information, communication, and related technologies, e.g. video and teleconferencing technologies in accessible formats; mobile phones; remote data-collection equipment and telemonitoring.

Expanding research and evidence practice (p. 119). Although the benefits of rehabilitation research can be significant, “validated research on specific rehabilitation interventions and programmes for people with disabilities (including medical, therapeutic, assistive, and community-based rehabilitation) is limited”. Rehabilitation research especially lacks randomized

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controlled trials being the most rigorous method of testing intervention efficacy. It is precisely this “lack of reliable research [that] hinders the development and implementation of effective rehabilitation policies and programme”. More research is needed in the areas of:

- linkage between rehabilitation needs, receipt of services, health outcomes (*functioning and quality of life*), and costs;
- accessing barriers and facilitators for rehabilitation, models of service provision, approaches to human resource development, financing modalities;
- cost-effectiveness and sustainability of rehabilitation measures, including community-based rehabilitation programmes;

Rehabilitation research hereby faces different challenges, including:

- lack of a common taxonomy of rehabilitation measures;
- difficulty to characterize rehabilitation outcomes and the breadth and complexity of measures;
- small number of valid outcome measures for activity limitations and participation restrictions that can be reliably scored by different health professions and within a multidisciplinary team;
- small sample sizes and extremely wide range of disabilities as well as diversity of conditions and contextual factors leading to inhomogeneous groups;
- the principle of including people with disabilities in the decision-making regarding rehabilitation requiring specific but less rigorous research designs and methods;
- the fact that controlled trials, which require blinding and placebo controls, are not feasible or ethical if services are denied for control groups (p. 119–120).

The valuable information drawn from rehabilitation research needs to be made available in form of good practice and clinical guidelines, health professional education curricula, and is especially a prerequisite in meeting evidence-based practice principles. Barriers to the integration of research evidence and the creation of guidelines lie in the lack of professional time and skills, challenges of finding a consensus and in adapting these to local contexts. Yet, where evidence is lacking a consensus process involving clinicians and consumers can lead to a consensus-based practice guideline, as was the case with the WHO guidelines on the provision of manual wheelchairs in less resourced settings (22). In addition, addressing barriers in rehabilitation research should involve end users in planning and research, use the ICF framework to develop a common language, incorporating a range of methodologies, systematically disseminating results, and expanding the clinical and research environment.

**Recommendations to improving rehabilitation (p. 121).** Finally the WRD gives a number of recommendations for improving rehabilitation, giving priority to ensuring “access to appropriate, timely, affordable, and high-quality rehabilitation interventions, consistent with the CRPD, for all those who need them.” The WRD argues that middle-income and high-income countries should focus on established rehabilitation services, “improving efficiency and effectiveness, by expanding the coverage and improving the relevance, quality, and affordability of services”. In lower-income countries, however, progressive realization should be the guiding principle and the focus should be on “introducing and gradually expanding rehabilitation services, prioritizing cost-effective approaches” (p. 121ff).

It is not possible to discuss in detail all recommendation of the WRD regarding rehabilitation (Table 1). However some implications for Physical and Rehabilitation Medicine and its international organization ISPRM are already clear at this stage and are summarized below.

**IMPLICATIONS OF THE WORLD REPORT ON DISABILITY FOR PRM**

The World Report on Disability, and in particular, the chapter on rehabilitation, strongly supports the efforts made by the international bodies of PRM towards a conceptual description of its goals and strategies within the framework of the ICF (8, 9, 11–16). This includes among others the:

- necessity to address to all dimensions of the ICF (*body functions and structures, activities and participation, environmental factors, and personal factors*);
- focus on enabling patients to fully participate in society;
- use of a patient-centered approach and the inclusion of patients into the decision making process;
- work in multi-professional teams and in their coordination.

The WRD favorably acknowledges the value of the multimodal approach of PRM (including medication, physical therapies, assistive technologies, education programs, and others) and PRM is confirmed to be appropriate to deal with the problems of people with disabilities (p. 100; 14–16). Furthermore the underlying concept of implementing Rehabilitation Medicine in all phases of medical care (*acute, post-acute, long-term*) and different types of services (*hospitals, rehabilitation centers, private practice, community and many others*) is taken up by the WRD (17, 18, 20, 21).

Further efforts are necessary, however, to optimize rehabilitation strategies to remove barriers for people with disabilities or experiencing disability, and to enable them to participate in all dimensions of society. PRM can offer much on a societal and an individual level. In accordance with the recommendations of the WRD this could mean for PRM:

- to help to increase awareness of the problems of people with disabilities and to contribute to the development of concepts to overcome these problems;
- to support the development of good practice models for rehabilitation services both at national and international levels (including evidence-based rehabilitation practice models);
- to develop good practice models for specific problems, e.g. models for enabling environments, specifically developing countries or after natural disasters;
- to transpose the comprehensive model of disability and rehabilitation into rehabilitation medicine and team integrated practices in all phases of disease treatment (*acute, post-acute, long-term*) and across all services;
- to further develop cooperation models among health professionals and to define standards for team-integrated work;
- to develop models and best-practice standard for the inclusion of people with disabilities into the decision making process in rehabilitation;
helping to remove barriers for people with disabilities in the health system, e.g. by teaching all health professionals (esp. non-specialists in rehabilitation) about disability and rehabilitation topics (e.g. by implementing rehabilitation topics in the undergraduate medical curriculum);
be informed by the best available evidence and experience to be able to form a comprehensive rehabilitation strategy that can really help make a difference in the lives of people with disabilities.

On one hand the WRD underlines the concept of PRM as a specialty that integrates both the medical and the functional perspective of disability. On the other hand, when looking at the multi-faceted picture of disability that the WRD draws on in various settings and especially in low and middle income countries it becomes unequivocally clear that there are many challenges ahead. Prioritisation, clear strategies and concrete action plans are key to eventually be able to reach the challenging goals being set by the WRD.

The role of health professional organizations

Besides other major stakeholders in the process of implementing the WRD’s recommendations, such as governments, service providers and users the WRD attributes a specific role to professional organizations such as the ISPRM (6, 7, 23, 24). These are essential for increasing awareness, participating in policy development, and monitoring implementation. Finally they should play an active role in international cooperation in order to share good and promising practices and to provide technical assistance to countries that are introducing and expanding rehabilitation services.

ISPRM as an agent of change

As a Non-Governmental Organisation (NGO) in official relation with WHO, ISPRM is in an unique position and consequently tasked to seize the mandates and actively support WHO’s efforts to implement the WRD’s recommendations both internally and externally. ISPRM is well suited to fulfill this role. In the past years ISPRM has given special attention to analysing and defining its role. To facilitate this work and to involve ISPRM’s constituency, a series of discussion papers were published in a special issue in Journal of Rehabilitation Medicine (24). These focus on ISPRM’s evolving role from the broader perspective of the world society and health (25), a policy process and policy tools suited to ISPRM’s evolving role and political mandate (26), an in-depth analysis of organizational challenges ISPRM faces as an international NGO in official relation with WHO (27), and ISPRM’s internal policy agenda in relation to its constituency and its external policy agenda in relation to international institutions, including the WHO, the UN and other NGOs in official relation with WHO (28).

Beyond disseminating and discussing the WRD’s content, ISPRM is called upon to lead an in-depth analysis of the WRD’s findings from the perspective of PRM to be then able in a second step to take on a leading role in the evidence informed policy dialogue with those policy and decision makers that hold the reins of rehabilitation strategy and resource allocation at their hands (6, 29). This implementation needs then to be complemented in a following third step both by action on an internal and external policy dimension (28). This can range from itself convening policy dialogues and events dedicated to discussing the WRD recommendations, delivering scientific and medical expertise in follow-up consultations, for instance, specific rehabilitation guideline development processes as well as contributing to political discussions in close cooperation with other nongovernmental organizations and especially the allied health professions (27). Evenly, ISPRM is tasked to carefully discuss implications for its own internal environment and consequently take action. Topics might for instance include the content of PRM curricula, rehabilitation research, and the removal of barriers to service delivery by further establishing links to and training capacity in geographical areas without PRM societies or other form of official representation (6, 27, 30).

Before this background and the challenges set out by the WRD, it is important to recall the added value ISPRM’s political action creates for its national and individual membership. In cooperation with other international professional organizations and global intergovernmental agencies such as WHO only ISPRM can work towards an international policy agenda that recognizes the need for a rehabilitation strategy including fostering a political and economic environment that allows PRM to provide timely and effective care worldwide for people experiencing disabilities (23).

ISPRM has contributed considerably to the WRD and was present at its launch as an organization in official relation with WHO. Being aware of its significance for the shaping of the world health political agenda for rehabilitation in the coming decade, ISPRM has established and specifically tasked a committee with the dissemination and implementation of this milestone publication. In this spirit and just four days after the launch of the WRD, ISPRM dedicated a half-day plenary session during the 6th ISPRM World Congress in San Juan, Puerto Rico to the presentation of the WRD. First reactions to its impact and implications for PRM were discussed and the ISPRM–WHO–WRD and the International Perspectives on Spinal Cord Injury (IPSCI) Dissemination and Implementation Committee met to discuss its work plan in analyzing and facilitating the implementation of the WRD’s recommendations. The in-depth analysis of the report will be complemented by efforts to systematically analyze and set implementation parameters, devise implementation tools and execute an implementation guideline that is to later serve as a template for the implementation of subsequent WHO reports, notably IPSCI (31).

CONCLUSION

The WRD is not only in itself a unique document but also its implications for PRM are of major importance. The WRD acknowledges the genuine role of PRM and its indisputable contribution to enhancing a person’s functioning and participation in life. Challenges lie in the delivery of rehabilitation services in parts of the world where none or only limited such services exist. And here PRM and ISPRM and especially its national societies are called upon to respond to the call. Both the extent and the quality of care needs to be addressed. This ranges from the provision of timely, cost efficient and effective treatment, the involvement of people with disability, family and care givers in the decision making process and enabling them through education to establishing a national rehabilitation strategy that can coordinate scarce resources and allocate them to where they can be most effectively be put to use. The PRM perspective is becoming increasingly integrated into disaster relief efforts (32, 33).
A first step in taking on these challenges has been made. Now a systematic and in-depth analysis of the WRD’s recommendations and an active exchange with WHO, the allied health professions and other partners of the WHO Disability and Rehabilitation (WHO DAR) network needs to follow. Results of that analysis need to be presented in a way policy and decision makers can use them directly and according to their needs (29). PRM has many competent and active voices. ISPRM as the international society of PRM can facilitate efforts to utilize the WRD to optimally benefit patients worldwide. With the WRD WHO has created a tool to implement central demands of the Convention on the Rights of Persons with Disabilities. It is now time for PRM to seize this exceptional opportunity to shine in its genuine role as facilitator to the right to health and full participation in life.

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