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ISPRM DISCUSSION PAPER

CHAPTER 3: INTERNATIONAL NON-GOVERNMENTAL ORGANIZATIONS IN THE EMERGING WORLD SOCIETY: THE EXAMPLE OF ISPRM

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SUMMARY

Using the International Society of Physical and Rehabilitation Medicine (ISPRM) as a case in point, the paper describes the complex world societal situation within which non-governmental organizations (NGOs) that adress health issues have to operate. In particular, as an international organization in official relation with the World Health Organization (WHO), ISPRM is confronted with a variety of responsibilities and a true world health political mandate. The accompanying rights need to be played out in relation to its own internal member organization and external allies. The theory of the world society and the current situation are briefly reviewed. The role of international NGOs within the world health polity, rehabilitation and Physical and Rehabilitation Medicine (PRM) is highlighted, whilst special emphasis is placed on NGOs in official relation with WHO. Functions, dysfunctions and challenges of international NGOs operating in the health sector are discussed. Against this background, key approaches to enhance ISPRM's political role are analysed. These include transparent and accountable development of the organization, the differentiation between internal and external policy relations, the harmonization of organizational structures and procedures, the consequential use of political structures available to influence WHO's agenda, and the identification of other policy players of major relevance to PRM in order to build strategic alliances with external partners and to enhance ISPRM's membership base.

INTRODUCTION

The notion that health is mainly a matter of chance, one's genetic endowment and personal lifestyle has slowly been complemented by the view that everyone has the right to the highest attainable level of health, or more simply, "the right to health" (1, 2). This is clearly seen in the various World Health Organization (WHO) initiatives promoting 'health for all' (3), i.e. the right to health care and other conditions nessecary for good health on an equal basis with others, for example access to food and clean water (4). Moreover, the United Nation (UN) Millennium Development Goals (5) and many UN treaties and declarations of human rights (2,4,6,7) may be cited. The rationale for such a right is that health, unlike other elements of human well-being, is not only a good thing in itself, it is instrumental to every life plan or aspiration that an individual might have (8). Moreover, health is increasingly conceived as being contingent on environmental factors at the micro, meso and macro level (9), including products, services and policies, of which the modification may facilitate the realization of rights to health (10–12). Health is herein increasingly understood broadly as a matter not merely of the absence of disease, but of optimal human functioning (10, 13, 14). This rephrasing of the often questioned WHO health definition (15–17) makes the link between health and disability explicit and provides a framework for classification and measurement (18, 19).

In the area of functioning and disability, we currently face a paradigm shift from a medical and charity approach to a "human-rights approach to disability" (6, 20). Sparked by the social model of disability (21), the focus has shifted from special to equal treatment and full social inclusion (22–24) of people with disability (25). This has recast the basic aim of rehabilitation as an essential health strategy of achieving and maintaining optimal human functioning (26), which in turn is closely linked to quality of life and – in the human rights context – to social inclusion and full participation of individuals experiencing disability (6, 25). Within rehabilitation, Physical and Rehabilitation Medicine (PRM) plays an essential role in implementing this fundamental strategy (26–28).

At the same time, rehabilitation in general, and PRM specifically, must operate against the background of persistent world social and political issues. These include continuous discrimination against persons with disabilities (6), the lack of adequate rehabilitation services, particularly in low and middle income countries of the world (6, 29, 30), conflicting defini-

tions and standards of PRM (27, 28, 31, 32), and the absence of adequate research capacity in disability and rehabilitation (33, 34). Non-governmental organizations (NGOs) can play a major role in addressing these worldwide problems, complementing the efforts of international governmental organizations (IGOs), and counterbalancing the self-interest of nation states and private enterprises (35–37).

As an international NGO of physicians (7) in official relation with WHO (38), the International Society of Physical and Rehabilitation Medicine (ISPRM) clearly has a humanitarian or civil-societal (36, 39, 40), a professional (27, 41) and a scientific (33, 34) mandate to addressing the obstacles to realizing the right to health and taking responsibility for its larger constituency. The three mandates are interlocked and include contributions to the establishment of rehabilitation services worldwide (29, 30), the development of PRM as a coherent and globally-recognized profession (27, 28), and the building of international research capacity in human functioning and rehabilitation (41, 42). Internationally, ISPRM is one of the professional health organizations that has put these global issues on its agenda (43) and has gone on record to contribute to realistic solutions (44).

Pivotal to the success of ISPRM in this endeavour is an explicit, systematic and transparent delineation of policies suited to exert influence from an international perspective. A necessary prerequisite for this is a realistic understanding of the current world societal situation and ISPRM's position in the world health policy. Without awareness of the complexities of the world situation, it would not be possible to identify policy tools with which ISPRM could make a constructive impact on health policy (45), or to develop those policy processes and organizational structures (45, 46) that ISPRM could use to define and implement its policy agenda (43).

The aim of this paper is to develop a comprehensive understanding of, firstly, the position of international NGOs in the world society at large, and the world health polity, rehabilitation and PRM in particular, and, secondly, of key approaches to how ISPRM can enhance its weight in health policy.

The specific objectives of this paper are: (*i*) to describe briefly the basic features of the current world societal situation; (*ii*) to describe the role of NGOs in general and of ISPRM in particular; (*iii*) to discuss potential functions and dysfunctions of NGOs within the world health system; and (*iv*) to outline basic approaches to address respective challenges. These include: (a) the set-up of a transparent and accountable discourse on ISPRM's structures and processes; (b) the differentiation between internal and external relations; (c) the harmonization of ISPRM's structures and procedures with WHO; (d) mechanisms to influence WHO's agenda; (e) the identification of other key external actors within the world health policy of major relevance to ISPRM; and (f) toe-holds to enhance ISPRM's membership base.

BASIC FEATURES OF THE CURRENT WORLD SOCIETAL SITUATION

Although this is obviously not the place for a complete description of the current world societal situation, a few fundamental observations may set the stage. Clearly, in today's world there are global resource dependences (47) and an uneven distribution of power and influence within global policy. There are also enormous inequalities of health and functioning around the globe (11, 30). At the same time, there are augmented opportunities for international NGOs such as ISPRM to intervene and contribute solutions.

The most obvious source of these opportunities is the global interconnectedness of communications, accompanied by a growing permeability of national boundaries with regard to economic, political, social and scientific exchange (48–50). This global interconnectedness of communications, actions and resources may be viewed as the essence of what has been labelled the world society (24, 51, 52). These, and related developments such as a world mass media system (53, 54) and global telecommunication and information technologies such as the internet (55), have contributed to what amounts to a world culture (56–58), or even a worldwide civil society based on universal humanitarian values (7, 8, 20, 40, 59, 60). The WHO Civil Society Initiative (CSI) (39, 61) is but one manifestation of this world culture.

World health system

Clearly, a world health system has emerged in recognition of global health risks, such as infectious diseases, environmental pollution, and poverty (62, 63). We are witnessing the development of global health governance (64) to deal with these global threats to health. Moreover, many behaviours and factors formerly not considered as relevant to health are now being seen as determinants of health, and thus as issues for future interventions and policies (65, 66). This is, for instance, expressed by a new understanding of functioning and disability (6, 10, 13, 14). The distinction of functioning and disability classifiable with WHO's ICF is herein orthogonally positioned to the classical distinction between health and ill-health (health condition in the language of the ICF) classifiable with WHO's International Classification of Diseases (ICD). So, for example, the prevention of health conditions in disabled persons becomes a public health issue (26, 27, 67, 68). In relation to the other rehabilitation professions and other medical strategies, PRM has a particular role within the health system in promoting functioning as well as diagnosing and treating health conditions (Fig. 1).

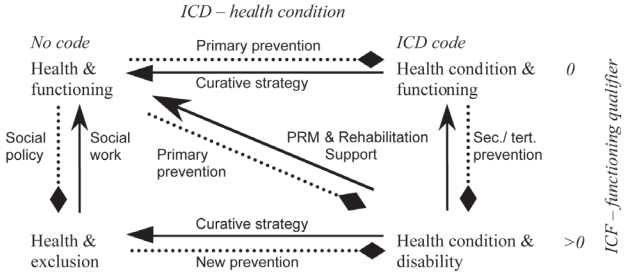

Fig. 1. Two different codes of the health system: health condition and functioning as targets of different health strategies. ICD: International Classification of Diseases; ICF: International Classification of Functioning Disability and Health; PRM: Physical and Rehabilitation Medicine.

On the level of the society, every decision, for example, whether to invest in coal-fired power plants, to promote sports or to balance the budget, once viewed as purely national economic or political issues, may now be conceived of as issues with direct health consequences and potential global impact (65).

At the organizational level, there are growing tendencies towards global diffusion and convergence of organizational structures and standards, such as WHO's ICF, arising from world cultural rationality (51, 56, 69–71). In organization sociology, this phenomenon has been labelled institutional isomorphism (70, 72). Examples of these tendencies are shifts within the legitimacy management of international NGOs that are related to the increased expression of universalism of human rights, such as the right to health.

Global health inequalities

By no means have these developments towards global connectedness and the convergence of values and aspirations disturbed the underlying inequalities of resources and unequal realizations of those values and aspirations such as health. Arguably, some developments, such as globalized capitalism or global health risks, have produced and enhanced many of the inequalities between world regions and social strata (73, 74). Others, such as the UN Convention on the Rights of Persons with Disabilities, are prescriptions rather than descriptions, which are actually articulated by international institutions *because* a great part of the world population is *de facto* excluded from their realization. Their impact is, nonetheless, global in nature: a particular state may disapprove of them and pretend to ignore them, but in the long run not taking notice is almost impossible. Many "ignored" international initiatives come back to state parties through "home grown" social movements (51) or prominent ambassadors. At the same time, different local cultures, including different cultural constructions of disability (75), continue to exist in the world society (76). These views sometimes struggle with world cultural imperatives (77), sometimes lead to different pathways of implementation and innovation. The latter is accounted for in the world cultural concept of diversity (57, 78), the former makes negotiations under the banner of "cultural sensitivity" inevitable (20).

Rehabilitation systems and low resourced settings

The World Health Assembly (WHA) Resolution 58.32 stresses "that 80% of people with disabilities, particularly in the child population, live in low-income countries and that poverty further limits access to […] rehabilitation services […]." (30). Against this background, the call of the UN Convention that "States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services" seems a Sisyphean task. The UN Convention explicitly recognizes "the importance of international cooperation for improving the living conditions of persons with disabilities in every country, particularly in developing countries […]" (6). ISPRM as a global PRM society is clearly addressed by these calls.

Very few data are available on rehabilitation services in low resource settings. Haig et al. (29), for instance, show that in Sub-Saharan Africa virtually no rehabilitation services are available. This means that even middle- and upper-class Africans cannot access medical rehabilitation. Obviously, there *is* a demand but *no* supply. The most difficult and important challenge, however, lies in addressing the needs of the many poor persons living with disabilities in low-resourced settings. ISPRM is thus called upon to make a two-fold contribution. On the one hand, the establishment of a market for rehabilitation services may be facilitated, while, on the other hand, markets need to be made accessible to the poor by fostering efficient service provision and compensating market failure through NGO and government provision of services or subsidies.

A major problem, also identified during a May 2008 meeting of WHO DAR (Disability and Rehabilitation) and professional rehabilitation organizations, including ISPRM, the World Confederation of Physical Therapists (WCPT) and the World Federation of Occupational Therapists (WFOT), is the "high level of migration from less developed countries (brain drain)", meaning "that trained professionals leave their countries for higher salaries and better recognition", as documented in the meeting minutes (79).

Against this backdrop, the potential role of international NGOs in health and rehabilitation is clear but challenging. There is a need to address inequalities of health and functioning and dysfunctions of current economic and political systems within the world society, while simultaneously accounting for cultural diversity. At the same time, world societal structures need to be utilized to reach this objective.

THE ROLE OF NGOS IN THE WORLD SOCIETY AND WORLD HEALTH POLITY

Worldwide, a constantly increasing number of NGOs or Civil Society Organizations (CSOs) have taken on roles and participated in achieving tasks once managed exclusively by states and international state initiatives (56, 61, 80, 81). NGOs are beginning to play a major role in bridging the gap between formulated policy principles and social and political reality (36, 80). They often expand beyond national boundaries and many are expected to uphold civil rights principles and world societal public interests against powerful trans-national business interests, national self interest, and conflicts between rich and poor areas (35, 80, 82).

NGOs may be defined as non-state organizations comprised of private individuals or associations that are organized on a non-profit and voluntary basis to achieve a common purpose. They operate at the local, national or international level, i.e. NGOs with a global membership and/or global scope of activities (35, 39, 56, 80, 83). According to WHO, NGOs (also CSOs) "include […] groups that represent consumers and patients, associations with humanitarian, developmental, scientific and/or professional goals and not-for-profit organi-

zations that represent or are closely linked with commercial interests" (84). Mixed goals NGOs, such as ISPRM, herein need to be aware of potential conflicts of interest between professional, humanitarian and scientific goals (85, 86), and may be challenged by purely humanitarian NGOs, such as disability rights organizations (87).The non-profit nature of NGOs leads to a "non-distribution constraint", i.e. surplus generated cannot be distributed to individuals in control of the NGO, but must be retained, reinvested (e.g. in a central office, research projects, or service provision) or granted to other NGOs (37).

NGOs in official relation with WHO

In the world health polity, NGOs in official relation with WHO, such as ISPRM, are of major political relevance in reaching "health-for-all" goals (84, 88). ISPRM's main external policy focal point is, and inevitably must be, the WHO and its policy agenda.

Through official relations with WHO, health-related NGOs are shifted from the periphery to the centre of the world health political system. They become subject to a defined set of rules and are eligible for the use of formal communication pathways with intergovernmental entities (24, 84, 88).

Fig. 2 shows the increasing number of formal relations of WHO with NGOs.

Protracted informal procedures are necessary to become an NGO in official relation with WHO. The following criteria for the admission of NGOs into official relations with WHO apply: (*i*) the main area of competence must be in line with WHO's purviews; (*ii*) the NGO shall "centre on development work in health or health-related fields"; (*iii*) shall not pursue commercial interests; and (*iv*) "the major part of its activities shall be relevant to and have a bearing on the implementation of the "health-for-all" strategies […]" (84, 88). When accredited, the NGOs have specific privileges, including the attendance of WHO meetings and duties such as the dissemination of WHO information. Table I summarizes WHO's principles for official relationships with NGOs.

NGOs in official relations are reviewed by WHO every 3 years. Based on this review, decisions on the continuance of the relationship are made (88). ISPRM thus needs to constantly evaluate its own agenda and activities in the light of this scrutiny and deliver respective reports to WHO.

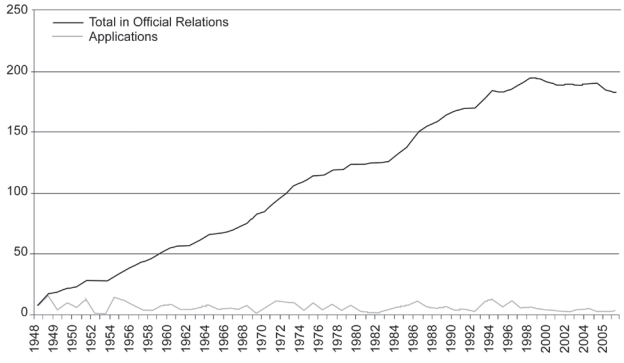

Fig. 2. Non-governmental organization (NGO) applications to official relation with the World Health Organization (WHO) since 1948. Source: WHO Civil Society Initiative (CSI).

Functions of NGOs in the world health system

To understand ISPRM's role in the world health system, it is helpful to differentiate between varying NGO functions.

Enhancement of public goods and creation of social capital. It has been highlighted that international NGOs are key players in the mobilization of transnational support for the enhancement of public or collective goods (37), otherwise exposed to the moral hazard (89) of global private corporations and short-term power interests (80, 82, 90) fostering adverse selection (91). This means that asymmetric information in favour of corporations or state parties may lead to quality deficits in goods and services provided and finally to a market of "lemons"(91), i.e. an underprovision of health-related goods and services at the highest possible quality level. International NGOs may thus play a vital role in compensating market as well as government failure (37). Moreover, because of their greater community involvement (92), they can be considered as generators of global social capital (37, 60, 93–95), i.e. stable networks of cooperation and collaboration in a community or region (96). This may lead to a particular effectiveness "in areas of health intervention that demand social action, public advocacy, or innovative and community-based responses to health problems" (35). In this light, it becomes obvious why "many IGOs originated as the result of [international] NGO activity", for instance UNESCO (78). Also, their world citizen character provides international NGOs with an outstanding role in monitoring the activities of IGOs, nation states and private corporations (80).

Contribution to world public opinion. International NGOs are specialists in the compilation and dissemination of documents and opinions on political issues recognized worldwide (97) such as poverty, landmines, torture, death penalty, and globalization itself. Many international NGOs thereby make extensive use of the possibilities of global mass communication and the internet. They, thus, importantly influence the world media and policy agenda (45, 98) and contribute to what might be called "world public opinion" (80). NGOs have the potential to spark social movements (60, 80) addressing specific health issues such as functioning and disability.

Resource mobilization, fast response, and health service provision. NGOs provide health technologies, expertise, human dedication and monetary resources not available to governments (61, 82). International NGOs appear to be much more flexible and faster in responding to international social problems than governmental administrations (80, 90, 99).They are particularly seen as innovators and value creators in financing and health service provision (82, 90).

More concretely speaking, NGOs can serve the function of service provision, for instance managing a hospital in a low resource setting (92). They can act as a supporter of other

Table I. *Excerpt of the World Health Organization (WHO) policy principles governing official relations with non-governmental organizations (NGOs)*

NGO/CSO Definition	Civil Society Organizations (CSO): "The increasingly accepted understanding of the term CSOs is that of non-state, not-for-profit, voluntary organizations formed by people within the social sphere of civil society" (1). NGO: "The term NGO is also commonly used to describe non-state, not-for-profit, voluntary organizations" (1).
Objective	"The objectives of WHO's collaboration with NGOs are to promote the policies, strategies and programmes [of WHO]; to collaborate with regard to various WHO programmes […]; to implement these strategies; and to play an appropriate role in ensuring the harmonizing of intersectoral interests among the various sectoral bodies concerned in a country, regional or global setting" (2) "to strengthen mutually beneficial relations at global, regional and national levels in ways that improve health outcomes, strengthen health actions and place health issues on the development agenda" (3).
Official relation	"WHO recognizes only one category of formal relations, known as official relations […]. All other contacts, including working relations, are considered to be of an informal character" (2). "The establishment of relations with NGOs shall be an evolving process proceeding through a number of separate stages […]" (2). "The Executive Board shall be responsible for deciding on the admission of NGOs into official relations […]"; § 2 (2). "the Board's Standing Committee on Nongovernmental Organizations […] shall consider applications submitted by NGOs […] and shall make recommendations to the Board; § 4.2 (2). "The Board, through its Standing Committee […], shall review collaboration with each NGO every three years and shall determine the desirability of maintaining official relations"; § 4.6 (2). "The Board may discontinue official relations if it considers that such relations are no longer appropriate or necessary […]";§ 4.7 (2).
Prerequisites	"The main area of competence of the NGO shall fall within the purview of WHO. Its aims and activities shall be in conformity with […] the Constitution of WHO, shall centre on development work in health or health-related fields, and shall be free […] commercial or profit-making nature. The major part of its activities shall be relevant to and have a bearing on the implementation of the health-for-all strategies […]"; § 3.1 (2). "The NGO shall normally be international in its structure and/or scope, and shall represent a substantial proportion of the persons globally organized […]";§ 3.2 (2). "The NGO shall have a constitution […], an established headquarters, a directing or governing body, an administrative structure at various levels of action, and authority to speak for its members through its authorized representatives. Its members shall exercise voting rights in relation to its policies or action"; § 3.3 (2). "Thus, organizations eligible for admission into official relations are […] international NGOs with a federated structure (made up of national or regional groups or having individual members from different countries), foundations that raise resources for health development activities in different parts of the world, and similar bodies promoting international health"; § 3.4 (2). "In exceptional cases a national organization […] may be considered for admission into official relations related work"; § 3.5 (2).
Privileges	"The privileges conferred by official relationship shall include: (*i*) the right to appoint a representative to participate, without right of vote, in WHO's meetings or in those of the committees and conferences convened under its authority […] this representative at the invitation of the chairman of the meeting or on his acceding to a request from the organization, shall be entitled to make a statement of an expository nature […] (*ii*) access to non-confidential documentation and such other documentation as the Director-General may see fit […] (*iii*) the right to submit a memorandum to the Director-General, who would determine the nature and scope of the circulation."; § 6.1 (2). In the event of a memorandum being submitted which the Director-General considers might be placed on the agenda of the Health Assembly, such memorandum shall be placed before the Executive Board for possible inclusion in the agenda of the Assembly"; § 6.2 (2).
Responsibilities	"NGOs shall be responsible for implementing the mutually agreed programme of collaboration and shall inform WHO […] if for any reason they are unable to fulfil their part […]"; § 7.1 (2). "NGOs shall […] to disseminate information on WHO policies and programmes"; § 7.2 (2). "NGOs shall collaborate […] in WHO programmes to further health-for-all goals"; § 7.3 (2). "NGOs shall […] collaborate with the Member States where their activities are based in the implementation of the national/regional/global health-for-all strategies"; § 7.4 (2).
Consequences for regional and national members	"These NGOs [regional or national NGOs affiliated to international NGOs in official relations with WHO] are, by definition, in official relations with the WHO Regional Office(s). They shall develop and implement a programme of collaboration with the regional and national levels of WHO to ensure implementation of health-for-all strategies at the country level"; § 5.1 (2). "Privileges similar to those stated above shall normally be accorded to national/regional NGOs having working relations with WHO regional offices […]"; § 6.3 (2). "A national organization which is affiliated to an international NGO covering the same subject on an international basis shall normally present its views through its government or through the international NGO […]"; § 6.4 (2).

organizations' initiatives, e.g. community-based rehabilitation programmes, by collecting funds, managing operations and liaison tasks of partners (92, 99–101).

Professional international NGOs such as ISPRM are also able to support initiatives by formally approving programmes in form of certifications (45). Their expertise can help funnel the attention of nation states toward such partners, initiating new funding streams. In addition, their function as an international advocacy organization helps to promote primary and grass-root healthcare concepts (80, 90, 92).

Advocacy of minority and powerless majority groups. A major element of government failure is the orientation of democratic governments towards the majority or the "median-preference voter" (37). Non-democratic governments, on the other hand, may design policies for a predominant minority. Against this backdrop, NGOs may act as advocates of powerless minority or majority groups (102). In the case of advocacy, a professional physicians' organization, such as ISPRM, needs to be cautious. Consultant doctors are in unique positions of power and are generally well-paid members of any society, implying a careful reflection of majority and minority positions in society (103).

Facilitating transnational research. As research organizations, international NGOs may serve the function of evidence collection with regard to best practice in different resource settings (104). This automatically brings macro and meso level environmental factors (9) into the research equation, e.g. through comparative analysis (105) or culturally sensitive meta-analysis or systematic reviews (106). In highly rationalized societal systems, such as health research or medicine, international NGOs may even be attributed greater authority than states, IGOs, or international corporations, giving them "a quasi official status in world society" (80). Examples are the Institute of Medicine (IOM) (107) or the Cochrane Collaboration for systematic reviews on healthcare interventions (108). It is, however, also important to note that some NGOs may be rather selective about health research and dissemination of findings and contribute to increasing knowledge gaps.

Societal division of labour and professionalization. NGOs representing a particular profession, such as ISPRM, have a pivotal function in defining the field of competence of the profession in question (109), describing appropriate education and training curricula (41), setting standards of knowledge and skills needed for professionalism (110), and drafting the division of labour with related professions (111). They also are of particular importance in prescribing ethical codes of professional conduct. Violation of such codes may then even go ahead with an exclusion from the profession, possibly backed by executive state powers (80). International NGOs play an additional role in the international standardization of professional requirements and ethics. On the international level, important future partners of ISPRM thus may be, for example, the International Standardization Organization (ISO) and the International Labour Organization (ILO) of the UN system. International NGOs may furthermore foster professionalization and moral conduct by designing "awards to recognize moral exemplars" (80).

Linking different societal sub-systems. NGOs are quite flexible in crossing borders of the societal division of labour. They are capable of linking perspectives from different societal areas, e.g. the linkage of environment, economy, health and development through a comprehensive approach towards water supply in developing regions (36). NGOs, moreover, bring players from different societal spheres together, encouraging comprehensive problem-oriented discourses (112). NGOs, and particularly international NGOs with their supplementary transnational view, serve as structural couplings between different societal sub-systems that usually follow their own logic (113). In a sense, ISPRM can thus be considered as a typical international NGO dovetailing scientific, professional, and humanitarian motives and approaches.

Successful initiatives. Successful initiatives of international NGOs in the health sector have been described primarily with regard to counteracting negative external effects derived from corporate practice, e.g. in tobacco control, distribution of pharmaceuticals, treatment access, and breast-feeding (82). Also their roles in vaccination programmes delivered through global private public partnerships (GPPP) (99–101, 112) and guideline development (114) have been highlighted.

Dysfunctions and challenges of international NGOs

The legitimacy, effectiveness and efficiency of international NGOs in addressing health issues and providing services have also been questioned, for instance under the label of voluntary failure (37).

Lack of formal authority. International NGOs often have no formal authority flowing from democratic, legal, bureaucratic or religious sources (56, 80). Moreover, they may not even be known or have a standing in the regions in which they want to operate, which may be the case with ISPRM in low resourced settings.

Philanthropic bias. Health-related NGOs may be biased because of conflicts of interest resulting from different levels of knowledge, influence, and resources of their partners (99). This may entail the neglect of the interests of low resource regions and minorities (35). Conversely, NGOs may focus exclusively on a particular minority group, leading to neglect of other stakeholders (philanthropic particularism) (37). Since they are often dominated by actors from the north-western hemisphere, NGOs may also act upon incorrect assumptions about the implementation capacities of developing countries (philanthropic amateurism) (37, 60, 80, 90), leading, for instance, to unsustainable health systems and brain drain of health professionals when the NGO withdraws its financial support (115, 116). International NGOs may be motivated not only by humanitarian concern, but also by a sense of mission regarding questionable ideologies (philanthropic paternalism) (37, 90). Since international NGOs provide collective goods they also face the problem that people may use services although they are not in need, or that former donors withdraw their donations because others have contributed in larger amounts than in the past (37, 117). This leads to difficulties in addressing the underprovision of services (philanthropic insufficiency) (37).

The moral entrepreneur's dilemma. In the course of their dependency on fundraising, NGOs face the dilemma of the "moral entrepreneur" (118), insofar as they must continuously show that they contribute to the solution of the problems they

address, although at the same time the problem still exists or is even more exigent than before.

The charity dilemma. Related to the moral entrepreneur's dilemma is a problem that may be called the charity dilemma. Charitable organizations that contribute to the inclusion of minorities in healthcare and beyond often need to depict the minority that will benefit from the organization's activities as suffering and helpless. With the help of this strategy sympathy can be aroused in potential donors and financial donations promoted. However, this marketing strategy itself contributes to the minority status of the group and may have negative effects on societal attitudes towards group members, such as people with disabilities. In a word, it may be disabling (119).

The professional standards dilemma. Professional standards and guidelines lead to the exclusion of those from the profession who do not adhere to the standards (111). High professional standards may be indeed desirable but may also produce systematic biases at the cost of professionals in low resource settings where professional training does not exist or does not have the form it has in developed countries. The dilemma may, however, be dissolved by introducing "minimal" and "gold" standards at the same time, whilst employing signature procedures for the "gold" standard (45).

KEY APPROACHES IN ENHANCING THE POLITICAL ROLE OF ISPRM

For ISPRM to fulfil its humanitarian, professional and scientific mandate, it is essential to understand these issues. Taking into account the situation of low resource settings, for instance, is a normative expectation expressed by WHO (35, 39, 82, 88) and is a crucial part of ISPRM's work with WHO (79, 120).

So, in order to avoid being a paper tiger, the management of legitimacy (121) and the development of effective working relations are inevitable.

Key approaches in this respect are: (*i*) to set up a transparent discourse on how to further develop ISPRM's organizational structures and policy relations; (*ii*) to differentiate between internal and external policy relations and in the latter case between input and output; (*iii*) to harmonize organizational structures and procedures in the light of the collaboration with WHO; (*iv*) to consequently use existing structures to influence WHO's policy agenda; (*v*) to identify other main external policy actors of potential relevance to joint initiatives and strategic alliances; and (*vi*) to develop a strategy to enhance membership.

Transparent and accountable development of ISPRM's policy

An explicit description, evaluation, and discussion of appropriate formal organizational and policy relations (46) and tools (45) are a necessary starting point to foster ISPRM's political power. The transparency of related discussions and developments is a must in international politics. This will provide ISPRM members and its global constituency with traceable information on these issues, thereby increasing their accountability for decisions (122, 123). In return, this discussion will enhance group cohesion and shared identification with ISPRM's visions and goals. On an inter-institutional and external level, this discourse will increase ISPRM's legitimacy as an organization (70, 124), one capable of meeting international standards of law and policy. More specifically, ISPRM's standing with WHO and the UN system will be enhanced. It will also help the organization to withstand scrutiny in the light of funding accountability and legal requirements (125, 126). In addition, it is hoped that this discussion will create a culture of open exchange and questioning within ISPRM, which in turn will lead to an improvement in its underlying structures and processes and enhance their efficiency, effectiveness and internal legitimacy (97).

Differentiation between internal and external policy relations

Organizations such as ISPRM are social systems that link membership to certain codes of conduct, e.g. those stated in the constitution, bylaws, or work contracts. Members are, for instance, expected to follow orders from people in certain positions regardless of their personal opinions. This connection of membership with expected conduct makes it possible to reproduce behavioural patterns on the side of the members in accordance with the purposes and rules of the organization in question (113, 127–129). In contrast with families, organizations are not an end in themselves but pursue goals in their external environment (124), such as "rehabilitation-for-all" in line with the WHO health-for-all initiative. Organizations thus differentiate between internal (self-reference) and external relations (other-reference). The former refer to the organization's members, e.g. national PRM societies, which may be seen as an internal environment. The term "internal environment" stresses the fact that, from an institutional perspective, an organization can never be in complete control of its members and sub-divisions. These often follow their own agendas and interests in micro-political arrangements and coalitions sometimes diametrically opposed to the organization's goals. External relations aim at influencing (output) or accommodating to (input) relevant corporate or individual actors within the external environment (113), e.g. influencing a WHO resolution vs accommodating to a UN convention. An organization's constituency normally includes members as well as non-members. The organization's relations to its constituency are thus partly internal and partly external.

It is suggested that ISPRM defines the structure of its policy process along similar lines and differentiates between an internal and external policy process and structure (45, 46).

Harmonization of internal and external structures and procedures

When deciding on the development of organizational relations, ISPRM's choices are constrained to pre-existing norms of its organizational environment. Moreover, ISPRM's choices directly affect its member societies on a national and regional

level. Besides such pressure towards institutional isomorphism (56, 70–72, 80), harmonization of internal and external structures and procedures can be seen as a powerful political means. By measures of synchronization with, for instance, WHO, the organization's legitimacy (70) and its attractiveness to new members and potential collaboration partners, including state parties, may be enhanced.

More specifically, this means that compatibility with WHO's goals needs to be secured by adapting to WHO's programmes on the one hand and influencing its agenda on the other. In addition, a mimicry of WHO's structures enables ISPRM and its member societies to appropriately communicate with WHO's bodies at all world levels. Indeed, regional and national member societies of an international NGO in official relation with WHO are themselves "by definition, in official relations with the WHO Regional Office(s). They shall develop and implement a programme of collaboration with the regional and national levels of WHO to ensure implementation of health-for-all strategies at the country level" (88). This signifies that collaboration of ISPRM with regional and national societies so that they meet WHO expectations is desirable for ISPRM as well as the societies in question. Explicitly, WHO places emphasis on the "harmonization of intersectoral interests among the various sectoral bodies concerned on a country, regional or global setting" through WHO-NGO collaboration (88).

Finally, an orientation towards other successful medical societies assures that respective public expectations are met. For example, the publication of clinical guidelines is not merely a matter of taste for an international medical society.

Enhancing external impact: influencing WHO's agenda

One of ISPRM's most powerful tools to influence the world health policy agenda is the right to submit a statement of an expository nature in the forefront of a WHO meeting and to submit a memorandum to WHO's Director General, who then decides on the nature and scope of its circulation (45, 88). An ISPRM representative can additionally be at a WHA session in question and make a statement, thus backing ISPRM's effort to influence the global health policy agenda. Although ISPRM does not have the right to vote in WHO meetings, it thereby has the potential to influence the agenda, as has been shown in the case example of the WHA Resolution provided elsewhere (38).

An equally important means to influence the agenda and decisions of WHO is the consultation with state parties entitled to vote in the WHA. ISPRM's relationships to national governments mediated through national and regional PRM societies is thus of central importance to ISPRM's external policy.

By means of coalition building with other NGOs in official relation with WHO, additional value can be attached to a particular request. ISPRM and its allies can cumulate their rights to send memoranda to WHO and make statements at the WHA. Other NGOs might also have good relations with governments in favour of the initiative in question, bringing an ally eligible to vote into the equation.

Fig. 3. shows different pathways by which political influence can be exerted on WHO.

Identification of other main external actors and seeking alliances

Apart from WHO, other external actors relevant to PRM and rehabilitation at large are to be accounted for in ISPRM's drive to become the world-leading PRM representative.

First of all, these are other actors within the UN system. These actors, and their relationships to each other are depicted in Fig. 4. Actors of potential interest to ISPRM, for funding possibilities or complementary fields of competence, have been highlighted.

Procedures similar to the ones depicted above in relation to WHO may be used to influence the global health agenda of other institutions of the UN system. Also, an official relation with some of these institutions may be pursued by working closely together with the UN Non-Governmental Liaison Service (NGLS) in Geneva (130).

Secondly, there are other NGOs, such as Rehabilitation International (RI), in official relation with WHO that share ISPRM's humanitarian, professional and scientific goals. Others may overlap with ISPRM's field of competence, such as the World Federation of Occupational Therapists (WFOT), and further can be seen as complementary to ISPRM's expertise, such as Disabled Persons Organizations (DPOs). The Electronic Appendix I shows selected organizations in official relation with WHO. It is indicated whether the society pursues health for all, professional, and/or scientific goals, if it is health condition specific or not, and if it may be a relevant source of fundraising.

Thirdly, the same should be done for NGOs in official relation with other relevant entities of the UN system, e.g. the International Labour Organization (ILO).

Fourthly, other relevant world societal actors need to be identified through literature and internet searches as well as the mass

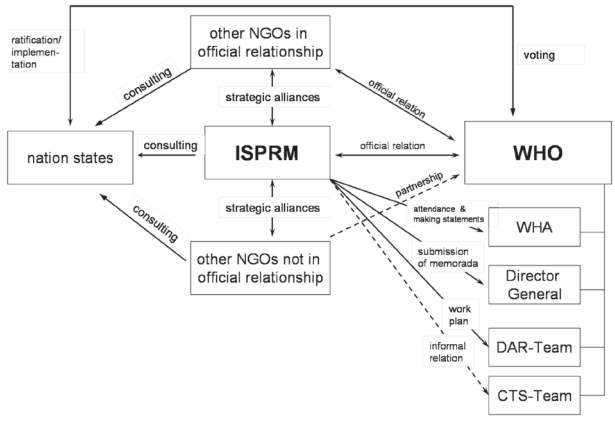

Fig. 3. Pathways of political influence on the World Health Organization (WHO) by a non-governmental organization (NGO) in official relation. CTS: Classification, Terminology and Standards; DAR: Disability and Rehabilitation; ISPRM: International Society of Physical and Rehabilitation Medicine; WHA: World Health Assembly.

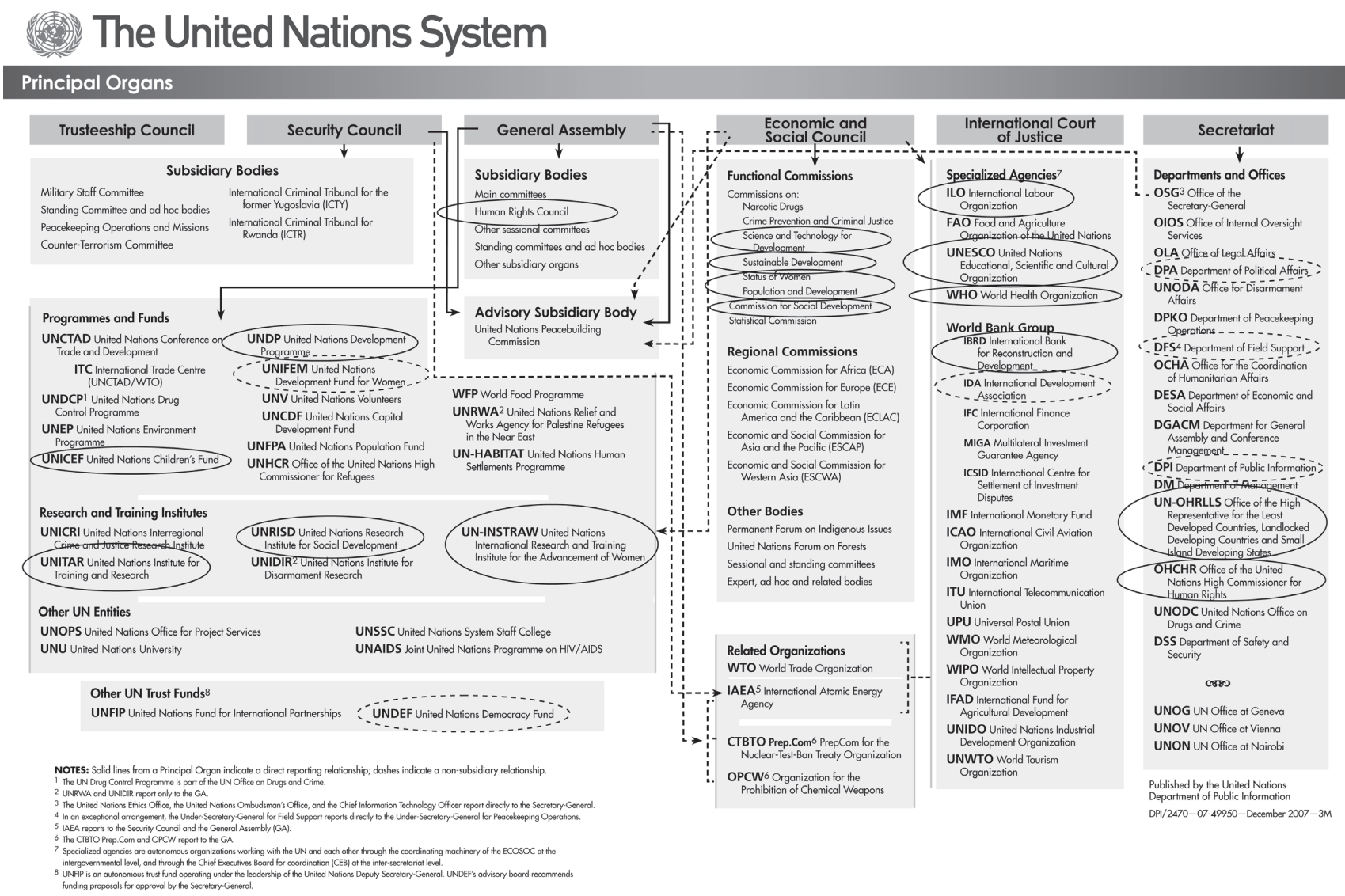

Fig. 4. United Nations system, highlighting potential partners for the International Society of Physical and Rehabilitation Medicine (ISPRM).
Source: www.un.org/aboutun/chart_en.pdf (modified).

media. These could encompass the Red Cross, Health Forum, Development Forum, Millennium Goals Circus, Club of Rome, Global Fund, OECD and so forth. The International Red Cross, for example, entertains a physical rehabilitation programme addressing rehabilitation issues in low resourced settings (131).

ISPRMs relationships with other IGOs and NGOs need to be based on mutually agreed terms and conditions to reach outcomes that are and are perceived to be beneficial (45). These relationships can be alliances and partnerships between 2 entities or jointly with multiple partners in form of a Global Private Public Partnership (99). ISPRM can join forces with a national NGO, for example, representing persons with disabilities in leading a campaign to influence a health ministry's agenda. A private company could be included to provide necessary funds for the campaign.

ISPRM can, in addition, establish an advisory agreement with intergovernmental organizations such as the European Union, on how to implement standards and guidelines into the national health systems. ISPRM could reach such a consultative status by sending representatives to relevant IGO hearings and consultations, offering its expertise and network as input and resource.

Similarly, fostering interlocking directorates (45, 132), by including representation of ISPRM on advisory or supervisory boards of other NGOs, IGOs and private corporations, is a step towards forging future coalitions and fostering advantageous relationships.

Scaling up the organization: enhancing membership

A major internal task in enhancing ISPRM's political influence lies in broadening its basis. A prerequisite is the identification and establishment of new internal relations to PRM societies worldwide.

As outlined above, along with the responsibilities of an organization in official relation with WHO, certain arguably beneficial rights are also passed to ISPRM. These have far-reaching implications, not only to ISPRM as the liaison representative to WHO on the global level, but also to national and regional societies that are automatically recipients of such rights. Their own expertise will be sought and actively called upon, adding to the societies' authority and influence as communicator and facilitator of health policy provisions. In order to broaden ISPRM's membership basis these advantages have to be clearly communicated. Regional societies need to be promoted (45, 133) and a procedure for official relations with ISPRM developed. Together with these regional actors, all national PRM societies and, where no society exists (29), initiatives worldwide should be identified and convinced to join ISPRM. The Electronic Appendix II contains a preliminary list of national PRM societies within different world regions. This provides the basis for efforts in enhancing ISPRM's membership.

CONCLUSION

This paper depicts a complex, sometimes contradictory and confusing, world societal situation within which ISPRM has to operate. In particular, as an international organization in official relation with WHO, ISPRM is confronted with a variety of responsibilities, but is also endowed with a world health political mandate.

Against this background, further steps towards ISPRM becoming an influential and central player within the world health polity at large and rehabilitation in particular include the elaboration of a policy process and respective policy tools suitable for ISPRM's projects (45) as well as the review of ISPRM's current organizational structures (46), as provided in subsequent papers in this special issue. On this fundament, ISPRM's policy agenda (43) can then be built.

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Electronic Appendices

No	Name of appendix	Available at
I	Selected NGOs in official relation with WHO (pdf-file).	http://jrm.medicaljournals.se/article/abstract/10.2340/16501977-0441
II	List of PRM societies and selected related institutions worldwide (pdf-file).	http://jrm.medicaljournals.se/article/abstract/10.2340/16501977-0442