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Commentary

Remodeling the ICF

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How disability is conceptually defined has far reaching social, economic and political implications. It could affect programs' eligibility criteria and the scope of legislation, and it matters very deeply to the disabled people's movement. Perhaps the most commonly used model of disability is from the International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organization (WHO).[1] The ICF is part of the WHO family of classifications. Although it was prepared as a classification, it is based on a model of disability, which is the focus of this comment.

The ICF is a bio-psycho-social model. It was a breakthrough that transcended the dichotomy between two competing models: the "medical model", focusing on the impairment or health condition as the disabling factor, and the "social model", developed by the disabled people's movement, focusing on disabling environmental barriers. The ICF provides an integration of the medical and social model, centered on the interaction between the individual with a health condition and the environment. While other interactional models have been developed,[2–4] the ICF is perhaps the most widely accepted.

The ICF is a conceptual model as well as a classification of functioning and disability. The classification aims to frame the collection of salient data on the lived experience of health conditions for research, policy or clinical practice.[1] We argue here that it is time to revise the ICF model. After presenting the main elements of the model and how it has been used, we explain the need to deepen and update our understanding of disability through the ICF model.

The ICF model

Under the ICF, disability is the result of the interaction of the environment and the person with a health condition. The different components of the ICF model and their interactions are shown in Fig. 1. This model starts with a health condition (disorder or disease) that within contextual factors gives rise to impairments, activity limitations and participation restrictions.

An impairment is defined as a "problem in bodily function or structure as a significant deviation or loss".[1] An activity is the execution of a task or action by an individual. Participation is understood in terms of an involvement in a life situation. Activity and participation domains include for example learning, mobility, self-care, employment. Functioning and disability are umbrella terms: Functioning covers body functions and structures, activities and participation, while disability includes all or any aspect of impairments, activity limitations and participation restrictions. Environmental factors refer to the entire background of an individual's life, the "physical, social and attitudinal environment in which people live and conduct their lives".[1] Environmental factors may be barriers or facilitators when it comes to the individual's functioning. Personal factors include gender, age, coping styles, social background, education, profession, and behavioral patterns. The ICF adopts a universal approach: it considers that all individuals are at risk of disability, to a greater or lesser extent, and thus there is a continuum of disablement.

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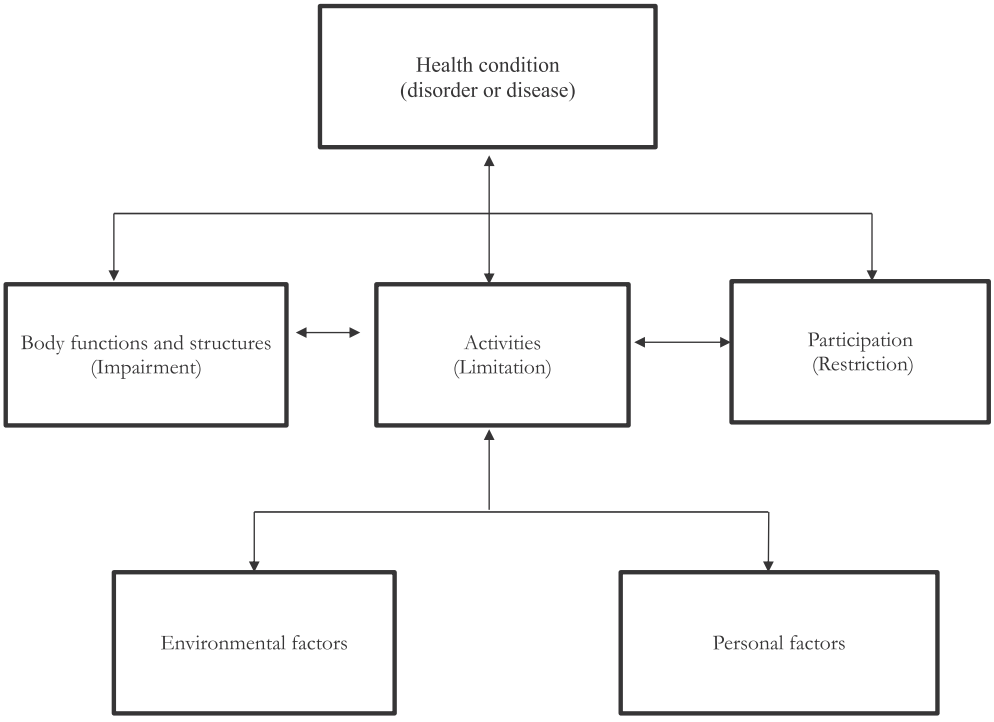

Fig. 1. Interactions between the components of the ICF.
Source: Adapted from WHO (2001)

The growing use of the ICF model

The ICF has gained considerable influence globally. It is used for a variety of objectives, in research, policy, education, clinical practice and rehabilitation.[5–9] It is sometimes adopted in public health curricula and endorsed by clinical associations as a conceptual framework.[10] In medicine, it is most often used in rehabilitation settings,[11] but also in other fields such as oncology.[6] Influential publications such as the World Report on Disability (WHO 2011) are based on the ICF. Cerniauskaite and coauthors[7] conducted a systematic review of the literature that uses the ICF. They found that the majority (30.8%) of publications were conceptual papers, 25.9% of papers were studies focusing on the description of disability of patients in clinical contexts and 9.2% of papers dealt with theoretical descriptions or practical applications of the ICF in contexts other than health (e.g. disability eligibility, employment, education, ICF training). The authors conclude that with the ICF, "cultural change and a new conceptualization of functioning and disability is happening". While widely used, the ICF has recently been subject to emerging critiques pointing towards the need to revise it.[3,12]

Why the ICF model needs revising

We consider that the underlying ICF model has fallen behind our developing understanding of disability. First, although the socioeconomic determinants of health conditions started to be understood before the World Health Assembly adopted the ICF in 2001, they have become more established since.[13] It is important to move upstream and include health conditions themselves as being influenced by (and influencing) personal factors and environmental factors. For instance, an environment where people have limited encounters with their family, friends and neighbors, could cause anxiety and depression (health conditions) in some people, and cause isolation (participation restriction) for other people with existing health conditions. Hence, there could be socioeconomic determinants that are central to explaining health conditions, as well as participation restrictions and activity limitations. Programs and policies addressing such determinants could bridge the gap between interventions aimed at preventing health conditions and those aimed at preventing their disabling consequences. In the current version of the ICF model (Fig. 1), health conditions are not in touch with environmental and personal factors. Moving health conditions to the same level as body functions/activities/participations and linked to environmental and personal factors would make it clear that health conditions do not arise in a vacuum. They are themselves the results of a vast array of factors, some biological, and some socioeconomic. In fact, there could be perhaps a broader notion of health, perhaps 'health states' or 'health deprivations' referring to health conditions and/or impairments. Moving personal and environmental factors to the top of the graph could also make them seem more central to the model, at least graphically.

In addition, there are a set of concerns about how person-centered the ICF model is. The emphasis on activities and participation appears limited to us. The ICF metric to assess human lives and how they may be affected by health conditions is based on body functions, activities and participations. If the ICF model is adopted, say to frame an intervention providing physical rehabilitation services to persons who had polio, then we would measure the activities and participations that result. But are activities and participations all that lives are made of? Where would states of being fit (e.g. being well nourished)? Activities and participation need to be replaced or supplemented by a more holistic concept, such as quality of life or wellbeing. Recent advances in approaches that define such alternatives such as Amartya Sen's capability approach should be considered.

What about the agency of the individual? What if the activities

and participations under consideration are not those that are valued? Clearly, agency cannot be ignored in a revised ICF model. The revised model has to consider whether an individual is able to act, participate or live on behalf of what matters to him/her. This is particularly important as there may be differences in agency experienced by persons with some health conditions or impairments (e.g. severe psychiatric condition).

Health conditions are very varied in their impact – some temporary, some permanent, some episodic, some degenerative. A revised ICF model needs to account for a dynamic view of the lived experience of health conditions.

Finally, as a disability model, the ICF model can be put into practice in various ways. For instance, the model can be used to frame a classification, a policy or program and survey measurement. The model should come with caution signs for operationalization. First of all, when put into practice in the classification, a policy or an intervention, it should be made clear that it offers a normative metric. The ICF model is not neutral, it is normative as it requires selecting relevant dimensions or aspects of lives. Not all dimensions of life may be specified and classified, and thus any implementation of the model (even the classification) does not, and cannot be expected to, provide an exhaustive account of the lived experience of health deprivations and requires selecting relevant dimensions of life. When put into practice, the ICF model also requires the normative judgment of setting thresholds for what will be considered a disability, whether in terms of impairments or its life consequences. For some implementation efforts, it may well make sense to vary the threshold according to cultural contexts and values.

In sum, we argue that the ICF model needs to be changed to reflect knowledge progress on the determinants and consequences of health conditions and our understanding of wellbeing or quality of life. The ICF model should gain more depth and breadth in how it portrays how lives may be affected by health conditions. Revisions to the ICF model likely would lead to changes to the ICF classification. We recommend that WHO puts together an international working group including persons with disabilities, their organizations, and the wider community of people affected by health conditions to consider revisions to the ICF, starting from its conceptual model.

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