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Published in:
Disability and Health Journal

DOI:
[10.1016/j.dhjo.2020.100978](https://doi.org/10.1016/j.dhjo.2020.100978)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2021

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Sykes, C. R., Maribo, T., Stallinga, H. A., & Heerkens, Y. (2021). Remodeling of the ICF: A commentary. *Disability and Health Journal*, 14(1), [100978]. <https://doi.org/10.1016/j.dhjo.2020.100978>

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Commentary

Remodeling of the ICF: A commentary

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ARTICLE INFO

Article history:

Received 9 December 2019

Received in revised form

22 July 2020

Accepted 23 July 2020

Keywords:

Classification

ICF

Functioning

Modeling

ABSTRACT

Since its publication in 2001 the International Classification of Functioning, Disability and Health (ICF) has attracted debate about the content and the model presented. After almost 20 years use, regular updating since 2008 and with the prospect of a new edition in 2020 there is increasing interest in the ICF as a tool to meet contemporary information requirements. Information on functioning is important across not only health systems, but all areas where change in functioning is important: education, employment, and social welfare for example. This commentary responds to the issues raised in a commentary by Mitra & Shakespeare in 2019 and supports review of the ICF in the current context by informing users and providers of data on human functioning how they might engage in the maintenance, updating, and modernisation of the ICF.

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Introduction

The International Classification of Functioning, Disability and Health (ICF) is generally accepted as the global standard language and framework for describing human functioning.¹ The World Health Organization (WHO) acknowledged in the manual that ICF is dynamic with room for improvement; writing “It should be noted that any diagram is likely to be incomplete and prone to misinterpretation because of the complexity of interactions in a multi-dimensional model¹”. Authors have engaged in debate about the conceptual model included in ICF since it was published: examples include Nordenfelt,² Whalley Hammell,³ Whiteneck,⁴ Heerkens et al.,⁵ and Sverker et al.⁶ The recent commentary by Mitra & Shakespeare⁷ and the support offered by the journal editors McDermott & Turk⁸ continue the debate in an environment changed by almost 20 years of ICF use and raises the prime question as to whether the time is right to remodel the ICF. The aim of this commentary is to put up ideas in response to specific points, to inform on ways to provide input to the updating and revision of the ICF and to encourage the involvement of disability constituencies.

“To classify is human”.⁹ We all classify as a way of ordering

objects or actions in our world. As Thomas Mann says, “Order and classification are the beginning of mastery, whereas the truly dreadful enemy is the unknown”.¹⁰ As pointed out by Mitra & Shakespeare,⁷ classifications and the way they are structured are for a particular purpose that is defined in social, cultural, political, and economic contexts that change. Any classification values some point of view and silences another.⁹ The ICF does not classify people but describes the situation of each person using health and health-related domains. Classifications as statistical tools need stability as well as the capacity to change to maintain currency, a balance between reflecting contemporary knowledge and continuity for longitudinal statistics. To address the balance there is a process of making iterative changes to the ICF classification annually and a less frequent process for revising the classification, such as happened when the first classification of disability, the International Classification of Impairments, Disabilities and Handicaps (ICIDH),¹¹ was revised to form the ICF.

The updated version of the ICF, anticipated in 2020, completes the process of merging the ICF for Children and Youth (ICF-CY)¹² with its parent classification.¹³ It is expected that more than 300 changes (affecting more than 600 categories) will have been made; showing that the ICF has been responsive to change since it was launched in 2001.¹⁴

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Ways to improve ICF through existing processes

There are extant ways in which to engage in processes to improve the ICF. Since 2008 most of the proposals have been to include categories from the ICF-CY. Other proposals are made by users of the classification when they identify errors, wish to add categories, illustrate the domain with additional examples, or need further differentiation of a category by adding sub-categories. The ICF updates are listed on the WHO website (<https://www.who.int/classifications/icfupdates/en/>). The update process is led by the Classification and Statistics Advisory Committee (CSAC).¹⁵ CSAC includes representatives of WHO Collaborating Centres from different countries, Non-Government Organisations, and additional experts selected by WHO (<https://www.who.int/classifications/en/>). People with disability and their organisations are encouraged to engage through existing processes.

Anyone can engage with the annual update process to add an evidence-based proposal and provide commentary on the proposals of others, once registered on the platform (<https://extranet.who.int/icfrevision>). All proposals are reviewed and discussed by members of WHO's Functioning and Disability Reference Group then; in an open process (normally May and June), all are welcomed to provide comments. After open discussion, the proposals are voted upon and, at the annual meeting of the collaborating centres for the WHO Family of International Classifications (WHO-FIC) in October, acceptable proposals are endorsed. This process includes changes in existing content but also a possibility to propose changes to the model. Proposals can be submitted year-round.

Is now the time to change the ICF model?¹

Whilst Mitra & Shakespeare⁷ and previous authors^{2–6} have discussed the ICF model and there are arguments in favour of change, one might ask whether the evidence is sufficient to warrant changing the model at this moment. The bulk of the published research is on the separate components, not the relationship between them.^{16–18} The number of studies using the ICF environmental factors is limited and without these factors a measure of functioning is meaningless. There is a paucity of data involving disabled people and their organisations and therefore a systemic bias in the evidence for the worth of the ICF to represent their situations. A recent review demonstrates that the ICF has undoubtedly changed thinking about functioning and disability, changed data collections and that new applications are emerging.¹⁹ The importance of involving persons with disability in the development of data collections and for truly representative research cannot be emphasised enough if the results are to influence changes to the ICF and its model.

Reflections on the building blocks of the ICF model

In their commentary, Mitra & Shakespeare state that “Under the ICF, disability is the result of the interaction of the environment and the person with a health condition”.⁷ In our opinion, the sentence fails to fully represent the model in two ways. Firstly, in ICF, functioning is the neutral umbrella term for body functions, structures and activities and participation, whilst disability is the negative

umbrella term for impairments, activity limitations and participation restrictions. Secondly, functioning as well as disability are the result of a dynamic interaction between contextual factors (both environmental and personal) and the health condition. We prefer to use the term functioning in recognition that the ICF is applicable to all. An emphasis on disability may give the impression that the ICF is for separate, minority groups rather than inclusive of people with different functioning and an equal right to participate in all facets of life.

Mitra & Shakespeare are correct in saying that there is no direct link between the contextual factors and health condition. We note that their Fig. 1, representing the ICF model, is not in accordance with the model in the ICF which includes arrows from environmental factors and personal factors to body functions/structures and to participation. In our view every component of the classification is important for the description of functioning and disability and can be related to each other.

The individual whose functioning is being described is central to data collected using ICF (as indicated in the Ethical guidelines for the use of the ICF¹), so the links will be indirect, e.g. work pressure (environmental factor) can result in increased blood pressure (body function) which, when a certain medically defined threshold is passed, is defined as a cardiovascular disease (health condition coded in ICD). Or, where a hidden health condition, such as HIV or mental illness is recorded (using ICD), a person may have no impairments, no activity limitations, but participation restrictions associated with the attitudes of individuals or groups, which act as barriers to participation.

One of the main concerns with the ICF model is that by having disease/disorder at the top many people see it as a medical representation, instead of biopsychosocial.⁵ Whilst the ICF model can be read from the top down there is nothing in the ICF manual that prescribes that the direction should be from top to bottom and left to right as is common in the English language. Indeed, data collectors generally start with personal factors (e.g. name, age, occupation); proceed to environmental factors (e.g. living arrangements, family); then move onto functioning; and only make a medical diagnosis taking account of previously collected information. Describing their own situation people focus on who they are and the factors affecting their situation.²⁰ Although it is not necessary, a simple flip around of the model can help to avoid wrong impressions²¹ as Mitra & Shakespeare suggest.

ICF is a multipurpose classification, but it does not include all concepts of importance to persons with disability. It is limited to the components of functioning and environmental factors. Other classifications in the WHO-FIC and broader United Nations Family of Classifications²² cover other important concepts. A suite of classifications used together in data collections can enhance the description of health and health systems. An advantage in using the ICF is to be able to describe the person's situation without necessarily ascribing a disease label thus enabling ICF use across settings such as in education, employment or for evaluating equity of access to services and for advocacy. Regarding the social determinants of health (SDHs), several are included in ICF as environmental factors (assets; physical and attitudinal environment; social supports, employment, and education) which together with salient life areas can influence activities and the extent of participation. Other classifications in the WHO-FIC also include SDHs; the ICD for example includes environmental risk factors. A problem in monitoring SDHs using ICF, is that the ICF environmental factors classification is not very detailed. However, there are possibilities to formulate new categories and sub-categories. Proposals to add work-related environmental factors are already in train.²³ ICF based data may contribute to the fulfilment of some of the indicators developed by WHO for monitoring SDHs and to monitor over time

¹ The ICF published in 2001 refers to ICF as ‘a framework’ (p3) a ‘model of functioning and disability’ (p18) and to ‘the scheme in Fig. 1’ (p19). Given that Mitra and Shakespeare refer to model and remodeling we have elected to use the term model.

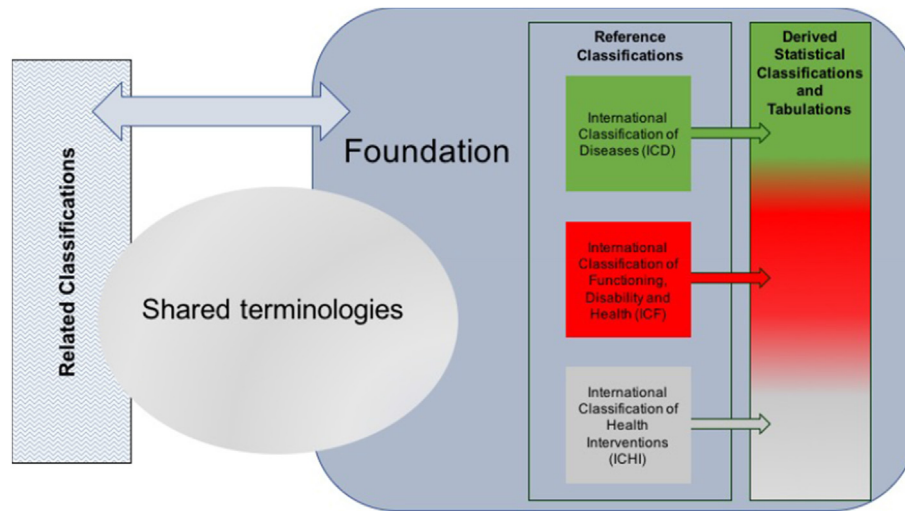


Fig. 1. Schematic representation of the WHO-FIC³³.

changing individual and population functioning as part of comprehensive data collections associated with interventions targeting SDHs.

Reflections on the ICF content

In addition to the ICF model, Mitra & Shakespeare comment on the ICF content. They express concern about how person centred the ICF is. In our opinion the design of a data collection is central to how the person's situation is represented. It is not a function of the classification per se. Annex 6 of the ICF highlights issues related to the collection and reporting of ICF based data. Mitra & Shakespeare remark on items such as being fit or well-nourished and suggest replacing or supplementing activities and participation by a more holistic concept such as quality of life or wellbeing. We will discuss these items in turn.

Fitness: according to ICF, fitness is a personal factor.¹ However, fitness as the quality of being suitable to fulfil a specific role or task may be seen as a summary of a range of ICF categories related to the life area for which a person needs to be fit. Fitness for participation in education requires one suite of categories, fitness for participation in sport another. ICF includes exercise tolerance functions, a measure of physical fitness.¹ This area of the ICF is being reviewed within the update process. Input to the proposals on this area of the classification are encouraged.

Being well-nourished: by emphasising disease and disorder, it may be forgotten that the ICF can also be used to describe functioning; so b530 weight maintenance functions can also be used to describe appropriate body weight. As permitted and encouraged in the ICF, additional qualifiers may be developed.¹ It is suggested that a generic qualifier with a positive scale for functions/structures, activities and participation, comparable to the positive scale for environmental factors would be useful. With a positive scale it would be possible to indicate 'better than normal' situations.

Quality of life: quality of life (QoL) is seen by some authors as a personal factor.^{23,24} For Huber et al., in the context of positive health, QoL is one of the six dimensions,²⁵ whereas Hendrikx et al. suggest that health consists of only two dimensions: QoL and daily functioning.²⁶ McDougall et al. suggest presenting QoL as a circle around the ICF model.²⁷ Undoubtedly QoL, "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" is important to everyone,

regardless of disability and may be measured using any of many instruments including those generated by WHO.²⁸ In the ICF WHO noting QoL as complementary with functioning suggested links with QoL as an area of future work.¹

The suggestion of Mitra & Shakespeare to connect ICF with the Capability Approach (CA) of Amartya Sen is interesting and already mentioned by other authors, including Saleeby²⁹ and Bickenbach.³⁰ This suggestion recognises the importance of understanding the central theme of the ICF: the concept of functioning; and one of the central concepts of the CA: 'functionings'. According to the CA 'functionings' are anything someone might choose to do or become even if, objectively, they are not valuable doings and beings.³⁰ When it comes to the conceptualization of functioning there is potential synergy between the two approaches. From the CA, we can appreciate that the capability to convert resources into genuine and realistic opportunities to pursue goals and life plans will influence one's 'functionings'. From the ICF, functioning – the result of a dynamic interaction with contextual factors and health conditions - is considered as an entity, capturing all that people *have* (body functions and body structures, e.g. sensory functions, eyes), all that people *do* (activities, e.g. tasks, skills) and all that people *are or aspire to be* (participation, e.g. being a parent, being an employee).³¹

The ICF provides opportunities to describe a status of functioning from different perspectives; that of the professional or a proxy (so called 'objective' or 'other-reported' perspective) and from the person themselves (a 'subjective' or 'self-reported' perspective). This can be important for recognising what needs to happen to change a situation. Think about a young disabled person who is taken to the shopping mall once a month in a group with other young disabled people. A professional, service provider or a carer might record a high level of participation. However, for the person with a preference to go to the local shops with a friend more frequently, the participation might be qualified at a lower level. The difference between the two perspectives can indicate what needs to be done to improve participation for the individual. To capture this, an additional qualifier for participation was developed in Australia to record a person's degree of satisfaction with participation in a domain of life, in relation to their current life goals. Satisfaction with participation corresponds to the person's own perspective on their participation and incorporates key concepts from the quality of life literature. It is essentially a summary measure in which are embedded the concepts of choice, opportunity

and importance.³¹ The ICF generic qualifier which is assessed against a norm may provide the 'objective' measure. This application of the ICF responds, at least in part, to the issue of agency for the individual within the ICF framework. Data collections may include measures to address quality of life and self-reported health status more comprehensively. To understand functioning means that the final judgment about how well a person is functioning must be primarily judged by the individual him/herself.³²

ICF going forward

When published in 2001 the ICF was the 'new kid on the block' with features of older classifications and features pre-empting a new generation of classifications. Technology has enabled the latest version of the International Classification of Diseases (ICD-11) to be based on a Foundation of terms such that various derived statistical classifications and tabulations can be drawn for different purposes (Fig. 1).³³ ICF is now playing catch up as, together with the incipient International Classification of Health Interventions (ICHI),³⁴ it is to be included in a common Foundation for the WHO-FIC.^{35,36} In October 2019 the WHO network of collaborating centres for the FIC discussed the modernisation of ICF, so it is timely and important for people with an interest in classification use to be engaged as the process goes forward.

Conclusion

We agree with Mitra & Shakespeare that the time is right to consider the ICF in the current context and the WHO-FIC Network is doing so. We would encourage greater involvement of persons with disability in the discussions on (re)modeling the ICF. The work underway is to be based on evidence in the peer reviewed literature, so it is critical that there is evidence that demonstrates the perspectives of disability constituencies and the critical importance of the environment. Involvement of persons with disability in the design of data collections and research is essential to this. The ICF update process is open so we would encourage commentary on the current proposals and submission of new proposals in line with the suggestions of Mitra & Shakespeare. Involvement of persons with disability benefitted the development of the ICF and would, in our opinion, be of value in its modernisation.

Funding

The authors have received no funding for the preparation of this manuscript.

Declaration of competing interest

The authors are members of their respective WHO Collaborating Centres for the Family of International Classifications. However, they have prepared this response in their private or professional capacities.

Acknowledgment

The authors thank the members of the WHO-FIC Network who have provided input to the discussions on this topic.

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