J Rehabil Med 2016; 48: 500–501

COMMENTARY

REPLY TO "FAIR OPPORTUNITIES, SOCIAL PRODUCTIVITY AND WELLBEING IN DISABILITY: TOWARDS A THEORETICAL FOUNDATION"

Shortly after the endorsement of the World Health Organization's *International Classification of Functioning, Disability and Health* (ICF) in 2001, sociologist and geographer Rob Imrie argued persuasively that the ICF is "conceptually underdeveloped … [in that] it fails to specify or evaluate, in any detail, the nature and adequacy of some of its theoretical underpinnings" (1). Imrie, in particular, pointed to the ICF notion of impairment, the so-called "biopsychosocial model" and the fundamental, governing principle of universalism. In each instance, he argued, the ICF is silent about both the intellectual source of these notions and their conceptual and theoretical underpinnings, and this may limit the practical, and theoretical, impact of the ICF on disability research and policy. Unless more is said about the biopsychosocial model, for example, critics will be free to claim that, by giving priority to biomedical determinants of disability, the ICF is merely another version of the so-called "medical model of disability".

Imrie was surely correct to point out that, by its silence, the ICF opens itself up to conflicting interpretations, not to mention gross misinterpretations. At the same time, one of the important strengths of the ICF is that it is "theory neutral", in the sense that it makes no theoretical or empirical claim about the disablement process itself; for example, it makes no claims about the relative significance of socio-cultural barriers as determinants of limited participation, but leaves these issues open for on-going research. ICF is, after all, primarily a classification, an international, standard language for collecting comparable information about disability. To infuse the underlying model of a disability classification with a specific theory that specifies the contours of the relationship between biomedical and environmental determinants of disability would potentially undermine this important function. Being congenial to different theoretical accounts of the disablement process, its determinants and consequence, arguably facilitates on-going research, which can only be a good thing.

Yet, there are limits to the degree to which ICF is congenial to substantive theorizing about the disablement process: the ICF model is not infinitely plastic. Thus, while all attempts to "theorize ICF" should be welcomed, care must always be taken not to undermine its basic construct of functioning, in terms of which disability is derived. It is also important to adopt the tactical rule, which was, in part, WHO's motivation for investing in the ICF in the first place, of avoiding the unproductive confusion that ambiguity, vagueness and undefined terminology can cause. No-one who is aware of the past 50-odd years of scientific work on the conceptualization of disability needs to be persuaded that an extraordinary amount of wasted effort has been spent because of the simple failure to define one's terms clearly.

With this preamble I turn to the paper by Siegrist & Fekete. They propose to engage ICF with a sophisticated, and fully developed, theory that elucidates the contribution of full participation in social life to individual wellbeing, and in particular the wellbeing of persons with disabilities. The bulk of their contribution is devoted to spelling out the details of this relationship (including in particular the potential impact of the psychological mediating factors of autonomy and recognition), and setting out the substantial body of empirical evidence in support of the linkage between engagement in "socially productivity and wellbeing". For concreteness, they also summarized the results of empirical research with persons with spinal cord injury, where the linkage is made between (re) entry into the labour market after the injury and heightened levels of wellbeing, life satisfaction and mental health.

This work is impressive and, without looking in detail at each contributing study, an outsider's most prudent response should be cautious acceptance. However, there is at least one troubling assumption that underlies Siegrist & Fekete's review, and that is this: "… in case of *disability*, lack of access to, and poor quality of, socially productive activities are more often experienced, and this fact is expected to result in lower overall levels of wellbeing." But is this expectation really warranted? There is some suggestion that as a matter of fact people with disabilities enjoy a fairly high level of wellbeing (the so-called "disability paradox" (2)). This has also been reported amongst persons with SCI (3). Indeed, it has even been argued that the assumption of low wellbeing is nothing more than a manifestation of disability stereotyping (4).

Yet, one should not lose sight of the point of Siegrist & Fekete's contribution, namely to "enrich the fundamental descriptive ICF framework with regard to the notion of participation by focusing on a core type of participation provided by the social environment, i.e. social productivity." The aim, as they state at the outset, is to supplement the ICF by providing "explanations of the relationships between its components, its determinants and longer-term outcomes". Siegrist & Fekete propose to filter "enabling" environmental conditions (in particular, socioeconomic position and policies) through Norman Daniels' notion of "fair opportunities" (5), which are instrumental in satisfying the need for autonomy and recognition in social productivity. This has the dual outcome of societal benefit and personal needs satisfaction, and in particular the need for self-efficacy and self-esteem, from whence wellbeing.

How does this model enrich the ICF's, purely descriptive, framework in which environmental factors interact with health

 doi: 10.2340/16501977-2107
 ISSN 1650-1977

conditions to produce levels of functioning in various domains (including domains of "social productivity", such as employment, volunteer work and civic obligations)?

Although Siegrist & Fekete confidently assume that "fair opportunities", or, more operationally, the implementation of provisions of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), "are instrumental in satisfying people's relevant needs, such as the need for autonomy and for recognition", they nowhere give evidence of this particular linkage. Perhaps it is unfair to require this of them (or anyone) since establishing an association either between an abstract doctrine of political philosophy, or even the implementation of a UN treaty, to something as vague as autonomy and recognition would require an enormous amount of conceptual clarification, operationalization and empirical work, none of which has been attempted. At best, very general socio-economic indicators, such as employment rates, have been suggested to estimate the impact of the CRPD, but these indicators identify phenomena very different from notions of autonomy and acceptance (which, of course, are themselves in need of conceptualization and operationalization). Finally, it is not immediately clear what the need for autonomy and dependence are in ICF terms, so that even if these associations could be established, it is not clear how this would help to explain the relationships between ICF components.

What would enrich the ICF would be an explanation of the relationship between environmental factors and levels of "social productivity" functioning. However, on this more concrete, and vital, linkage, Siegrist & Fekete recognize that, at least in the case of SCI, we simply have no way to identify "enabling conditions of labour market participation". Indeed this is major gap that ICF-based research needs to fill. We can confidently measure the positive impact on performance of many forms of assistive technology for specific domains, but it is beyond our current ability to track, let alone assess and measure, the impact of social policy changes on any domain of participation. That is where theories to supplement the ICF would be very much welcomed.

At the outcome end of Siegrist & Fekete's theoretical model is wellbeing, which of course is not an ICF component. Although there was some early agitation to include quality of life or some other subjective component within the ICF classification (6), this suggestion was never followed up. At the time of ICF's development, WHO was very reluctant to risk the controversy that would inevitably result if the ICF components went beyond the purely objective realm of biomedical phenomena (Body Functions and Structures) and observable, objective or at least objectively operationalizable phenomena (Activities & Participation, Environmental Factors). (This may also have been part of the reason why Personal Factors were left undeveloped).

Although wellbeing is not an ICF component, it is indeed a plausible, long-term outcome that, intuitively, may be linked to levels of a person's functioning. However, recalling the early tactical remark, providing evidence of an association between ICF functioning and wellbeing, coupled with a theoretical explanation of this link, for example, in terms of the positive impact of self-efficacy and self-esteem, or similar account, very much depends on how we characterize wellbeing. Needless to say, there is no agreement on what this term means, let alone how it might be assessed and measured. There are versions of wellbeing, or subjective wellbeing, that some have suggested may be measureable (7), but most other accounts are notoriously less so. The usefulness of the notion depends very much on whether we can rely on the empirical associations that seemed to be revealed by research. However, at least with respect to the ICF, it remains to be seen why entering into these controversial waters would "enrich the fundamental descriptive ICF framework".

REFERENCES

1. Imrie R. Demystifying disability: a review of the Intenational Classification of Functioning Disability and Health. Soc Health Illness 2004; 26: 287–305.
2. Albrecht GL, Devlieger PJ. The disability paradox: high quality of life against all odds. Soc Sci Med 1999; 48: 977–988.
3. Ville I, Ravaud J-F, Tetrafigap Group. Subjective well-being and severe motor impairments: the Tetrafigap survey on the long-term outcome of tetraplegic spinal cord injured persons. Soc Sci Med 2001; 52: 369–384.
4. Amundson R. Quality of life, disability, and hedonic psychology. J Theory Soc Behav 2010; 40: 374–392.
5. Daniels N. Just Health. New York: Harvard University Press; 2008.
6. Ueda S, Okawa Y.The subjective dimension of functioning and disability: what is it and what is it for? Disabil Rehabil 2003; 5: 596–601.
7. Dolan P, Metcalfe R. Measuring subjective wellbeing: recommendations on measures for use by national governments. J Soc Pol 2012; 41: 409–427.

Accepted May 4, 2016; Epub ahead of print May 13, 2016

Jerome Bickenbach, PhD, LLB
From the Swiss Paraplegic Research, Guido A. Zäch Institute, CH-6207 Nottwil, Switzerland.
E-mail: jerome.bickenbach@paraplegie.ch