

Guest Editorial

The Challenge of Understanding the Disablement Process in Older Persons

Commentary Responding to Jette AM. Toward a Common Language of Disablement

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DISABILITY is caused by a diverse set of conditions and diseases and can affect people across the full age spectrum. Understanding the development of disability, the impact of disability on the individual and ways to both prevent disability and mitigate the impact of disability on quality of life are high priorities. But disability is a complex and challenging process to study, especially when it develops over years or decades. Researchers who study disability face many challenges and need all the help we can give them. A key tool to support this research is a simple, clear model to help examine steps along the pathway to disability. Such a model should provide measurable concepts along the pathway that are unambiguously operationalized. This approach is critical to making discoveries that can turn into useful interventions.

In this issue of the Journal, Dr Jette, a leader in this field, presents a thorough review of the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) (1), currently proposed by the WHO as just such a model. This review is an accurate representation of the WHO report on the ICF, which, as Dr Jette points out, the American gerontology community needs to become more familiar with. We agree on the value of having an internationally agreed-upon framework for the study of disability but remain unconvinced that the study of disability in the older population will be enhanced by utilizing the ICF in its current form.

There are some extremely valuable and innovative aspects of the ICF. At the most basic level, the ICF is really about changing the language we use in approaching disability, and we should not underestimate the strong effect that language has in perceptions and reactions to disability (2). The main domains are framed in a neutral way so that each has positive as well as negative aspects and can represent people across the functional spectrum. The concept of par-

ticipation provides a strong focus on the ultimate goal of maximizing the opportunities for all people with limitations. This clearly emphasizes the effect of the environment and society on the experience of disability, which has received insufficient attention. It is very advantageous to be able to use participation as a positive attribute and be able to study how improvements in participation can induce a positive feedback loop that benefits impairments, health behaviors, and further adaptations. The concept that disability should not be a specific point on the pathway but rather an overlying concept that refers to the whole process has value, although it creates some confusion because of the very long usage of disability to reflect more specific issues. Finally, the retention of the concept of impairment, defined as problems in body functions and structure, seems important, as it helps to bridge the gap between health conditions and functioning of the whole person.

Dr Jette encourages us to move away from the Nagi model and embrace the ICF as the ICF was developed by a worldwide consensus and will be used in many other countries. However, it would be valuable to go beyond the argument that everyone else is doing this so we should be too. We are in a dilemma with the ICF as there is not much enthusiasm for it in the U.S. gerontological community. At this point, we need to choose between simply dismissing the ICF as not useful for our work or taking the more constructive option of attempting to understand where the limitations are and whether they can be remedied.

Probably, the biggest issue regarding the limitations of the ICF has to do with the aggregation of "activities and participation" into one domain in the WHO framework. Dr Jette notes that they do have separate definitions and describes how WHO organizes them into subdomains but then goes on to explain that the subdomains (which he lists and which include areas as diverse as self-care, mobility, communication,

interpersonal interactions and community, social and civic life) are the same for both the activity and participation domains. This is very difficult to comprehend and more help is needed if we are to understand how we could ever apply this to patients or research subjects in a way that improves our knowledge about pathways to disability. The ICF documentation itself simply lumps all of these domains under the general category “activities and limitations” and makes no attempt to assign specific elements to each separately. A very well-written review of the problems in this regard comes from the Institute of Medicine (IOM) report *The Future of Disability in America* (3), which endorsed the use of the ICF but had major concerns about it. Several sections of that report are worth citing verbatim:

A first and well-recognized aspect of the ICF that needs further development involves the interpretation and categorization of the concepts of activity and participation. Reflecting the difficulty that the ICF developers encountered in differentiating the two concepts, the final ICF document presents them as conceptually distinct with different definitions, but the actual classification scheme provides a single combined list of life areas that are not specifically linked to one concept or the other (page 42).

Several researchers have criticized the lack of a clear operational differentiation between the concepts of activity and participation in the ICF as theoretically confusing and a step backward from earlier disability frameworks (see, e.g., the work of Jette et al. [2003] (4), Nordenfelt [2003] (5), Simeonsson et al. [2003] (6), Barral [2004] (7), Schuntermann [2005] (8), and Whiteneck [2006] (9)). Operational differentiation among concepts and the ability to measure each concept precisely and distinctly is important for clear communication, monitoring, and research. If the differences between these two concepts are not clarified or otherwise resolved in some coherent fashion and if different users distinguish these core concepts in different ways, the goal of a universal and standard language for classifying individuals with respect to the burden of health conditions will remain unfulfilled. (page 43)

Although this committee does not endorse any particular approach to resolving the problem, it believes that the lack of operational differentiation between the concepts of activity and participation is a significant deficit in the ICF. Developing the conceptual base for such differentiation or substituting some alternative conceptualization is a key step that needs to be taken to clarify and refine the ICF so that it provides a better foundation for disability monitoring and research. (page 44)

As far as we are aware, despite ongoing work on the issues raised by the IOM report, a solution that is widely accepted and acknowledged has not emerged. We laud the efforts of Dr Jette to be constructive in this regard. A solution that is offered in his commentary is to use the Nagi model as a guide as to how to partition and interpret the ICF. Although this clearly gives us help in our struggles to utilize the ICF, our first reaction to this is to ask why is it worth moving from the Nagi model to the ICF when the ICF needs to be propped up by the strength of the Nagi model. As

demonstrated in his table 1, Dr Jette proposes that functional limitation in Nagi is equivalent to activity limitation in ICF, and disability in Nagi is equivalent to participation restriction in ICF. This would work if activity and participation had been well characterized and operationalized in ICF, but when one peruses the list of items that are all under the activity and participation domain in ICF (the “single combined list of life areas” referred to earlier by the IOM report), there is no guidance as to what belongs to activity and what belongs to participation. The Nagi model has been successfully used as a theoretical pathway that was empirically tested in multiple data sets. For example, evidence demonstrates the predictive value of disease for impairment (arthritis causing reduced strength) (10), of impairment for functional limitations (reduced strength leading to reduced gait speed) (11), and of functional limitations for disability (lower extremity limitations leading to activity of daily living and mobility disability) (12). The Nagi model also provides a framework for understanding how environmental factors and use of compensatory strategies modify progression along this pathway (13).

It is worth noting that it took years and a large body of evidence before the Nagi model was widely accepted. This kind of empirical work will be challenging for the ICF because activity and participation exist in one large mass of functions, making it difficult to test whether the ICF validly represents a pathway along which people actually travel as they develop disability. But we may, in fact, be premature in thinking that the ICF should be used at all as a model of a pathway. In reading the ICF “bible” (14), the study of the disablement process is really never clearly mentioned and in fact the much publicized figure of the model (figure 1 in Jette commentary) seeks to show that all aspects of disability are related to all other aspects, with all arrows going in both directions. One can only assume from this that a decision was made to not impose the concept of a pathway at all on the model and in fact the terms “disablement” or “disablement process” are not used. Rather, the ICF uses its framework to support the new language of disability that it introduces.

With the emphasis on developing a new language of disability, we find it understandable why the ICF developers made the decisions they did. From the perspective of a person who is already disabled, especially when the severity of disability is fully established and, at the current state of the art, cannot be substantially changed, the impetus is clearly on creating an enabling environment that allows maximal activity and participation. Focusing on the impairment and functional limitation may be seen as a stigmatization of the individuals, a sort of guilt attribution that may be used as an excuse to avoid creating a more hospitable and facilitating environment. Also, in the disability that occurs in young and middle age, with few exceptions, the focus on disability prevention is on the prevention of diseases and trauma, which is separate from issues regarding the course of the disablement process. Finally, because most of the disability

in young and middle age is limited to one or a few physiological domains (e.g., neurological with the energetic and cardiovascular systems completely intact or other patchy combinations of impairment), there is good opportunity for compensation. This means that an enabling environment can truly allow a satisfactory and independent life. Legislation, architectural design, environmental design, and city planning that maximize activity and participation make a lot of sense here. Ultimately, older people with disabilities can also benefit from an enabling environment, but in very old frail individuals there may be more limitations in this regard. The chances that changes in the environment are enabling are less because the disablement process is not limited to one physiological aspect of function but crosses over many, making the chances for compensation more limited. For example, use of an enabling environment may require good cognitive function, strong upper extremities, manual dexterity, and good vision that many disabled older people do not have.

Another challenge faced in dealing with the one model fits all approach is that catastrophic disability, which is more common in younger individuals, and progressive disability (15), whose prevalence increases with age, may require very different perspectives. When disability occurs suddenly, there may simply not be much value in considering the disablement process. However, for progressive onset of disability, which may take years, an individual can be tracked sequentially with longitudinal data to identify passage through different stages. As proposed by Nagi, when disability develops over time, it is possible to identify people without disability who have functional limitations and people without functional limitations who have impairments. The beauty of this framework is that it allows for appropriate interventions at different points in the pathway. An example of this is the Lifestyle Interventions and Independence for Elders (LIFE) study (16), a randomized controlled trial, which selected older persons who were not yet disabled but who had objective evidence of functional limitations that in previous observational studies, framed on the Nagi model, were proven to denote elevated risk of new disability onset (12).

Dr Jette has initiated a constructive approach to making the ICF more applicable to aging research. Further, substantial modifications will be needed to support the kind of advances made in understanding the disablement process that have come from using the Nagi model. Speaking a different language is never a good avenue for collaboration, especially in science, and there would be many advantages if aging researchers used the same language as others who deal with disability issues. However, the attempt to reach reconciliation should be honest and should be based on empirical findings coming from real world data; we may find that making the transition is not worthwhile. Ultimately, the ICF will be used in aging research if it can be operationalized in a way that it promotes our understanding of the disablement process as it occurs in older people.

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REFERENCES

1. Jette AM. Toward a common language of disablement. *J Gerontol A Biol Sci Med Sci*. 2009; doi:10.1093/gerona/glp093.
2. Iezzoni LI, Freedman VA. Turnig the disability tide. The importance of definitions. *JAMA*. 2008;299:332–334.
3. Institute of Medicine. 2007. *The Future of Disability in America*. Washington, DC: The National Academies Press.
4. Jette AM, Haley SM, Kooyoomjian JT. Are the ICF activity and participation dimensions distinct? *J Rehabil Med*. 2003;35:145–149.
5. Nordenfelt L. Action theory, disability and ICF. *Disabil Rehabil*. 2003;25:1075–1079.
6. Simeonsson RJ. 2006. Defining and classifying disability in children. In MJ Field, AM Jette and L Martin (eds). *Workshop on Disability in America: A New Look*. Washington, DC: The National Academies Press 67–87.
7. Barral C. ICF: internal and external obstacles to implementation. Presented at: Tenth Annual NACC Conference on ICF; June 1–4, 2004; Halifax, Nova Scotia, Canada. [Online]. Available: http://www.cihi.ca/cihiweb/en/downloads/Catherine_Barral.pdf [accessed May 16, 2009].
8. Schuntermann MF. The implementation of the International Classification of Functioning, Disability and Health in Germany: experiences and problems. *Int J Rehabil Res*. 2005;28:93–102.
9. Whiteneck G. 2006. Conceptual models of disability: past, present, and future. In MJ Field, AM Jette and L Martin (eds). *Disability in America: A New Look*. Washington, DC: The National Academies Press 50–66.
10. Messier SP, Glasser JL, Ettinger WH, Craven TE, Miller ME. Declines in strength and balance in older adults with chronic knee pain: a 30-month longitudinal, observational study. *Arthritis Rheum*. 2002;47:141–148.
11. Gibbs J, Hughes S, Dunlop D, Singer R, Chang RW. Predictors of change in walking velocity in older adults. *J Am Geriatr Soc*. 1996;44:126–132.
12. Guralnik JM, Ferrucci L, Simonsick EM, Salive ME, Wallace RB. Lower extremity function in persons over the age of 70 years as a predictor of subsequent disability. *N Engl J Med*. 1995;332:556–561.
13. Verbrugge LM, Jette AM. The disablement process. *Soc Sci Med*. 1994;38:1–14.
14. World Health Organization. 2001. *ICF: International Classification of Functioning, Disability and Health*. Geneva: World Health Organization.
15. Ferrucci L, Guralnik JM, Simonsick E, Salive ME, Corti MC, Langlois J. Progressive versus catastrophic disability: a longitudinal view of the disablement process. *J Gerontol A Biol Sci Med Sci*. 1996;51:M123–M130.
16. The LIFE Study Investigators. Effects of a physical activity intervention on measures of physical performance: results of the Lifestyle Interventions and Independence for Elders pilot (LIFE-P) study. *J Gerontol A Biol Sci Med Sci*. 2006;61:M1157–M1165.

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