

## COMMENTS FROM WHO FOR THE *JOURNAL OF REHABILITATION MEDICINE* SPECIAL SUPPLEMENT ON ICF CORE SETS

B. Üstün, S. Chatterji and N. Kostanjsek

*From the Classification, Assessment, Surveys and Terminology Team, World Health Organization, Geneva, Switzerland*

J Rehabil Med 2004; suppl. 44: 7–8

Health indicators have traditionally focused on deaths and diseases. While mortality data or diagnostic data on morbidity are important in their own right, they do not adequately capture health outcomes of individuals or populations. Diagnosis alone does not explain what patients can do, what they need, what their prognosis will be and what the cost of treatment will be. To deal with such questions, the International Classification of Functioning, Disability and Health (ICF) (1) was developed to provide a common framework for health outcome measurement. The ICF enables us to capture information about the functioning of individuals. What happens when people get ill? What they can and cannot do due to their health condition? What difference do the treatments make? To answer such questions in a clinically relevant manner and to compare across individuals, treatments or over time we need common definitions, anchor points and a consensus on the conceptual framework.

The concept of measuring functioning, disability or health is not new. There are hundreds of assessment tools. Mostly clinicians in different specialties have developed condition-specific assessment tools (e.g. Arthritis Impact Measurement Scale, AIMS 2; Hamilton Rating Scale of Depression, HAMD; McGill Pain Assessment Questionnaire, MPQ; Outcome Measures in Rheumatology Clinical Trials, OMERACT). There are also some generic measures (SF-36, Nottingham Health Profile, EuroQol-5D). These measures have proven useful to track outcomes, but they are neither comprehensive nor do they fully map to the ICF. The result, well-known and much criticized, is “data silos” in which assessment data acquired in one episode of care – emergency, medical, rehabilitative, out-patient, and community clinical care – cannot be carried over to another episode of care involving a different clinical focus. To compare outcome data across diseases and interventions we need a common framework that will serve as a “Rosetta Stone”. The ICF makes it possible to link together these data across conditions or interventions, eliminating the frustrating data silo effect, and making for more efficient, transparent, and cost-effective healthcare.

A classification needs to be exhaustive by its very nature and becomes very complex for daily use unless it is transformed into practice-friendly tools. For example, a clinician cannot easily take the main volume of ICF and consistently apply it to his or her patients. In daily practice, clinicians will need only a fraction

of the categories found in the ICF. As a general rule, 20% of the codes will explain 80% of the variance observed in practice. With this need in mind, WHO has already created a series of instruments based on the ICF, like the ICF Checklist and the WHO Disability Assessment Schedule II (WHO DAS II) (2).

The ICF Checklist is a practical translation of the ICF for clinical practice (3). Items from the classification were chosen by experts to list the most commonly used domains, and later field tested to verify the selection and make additions of missing items. The ICF Checklist gives a thumbnail sketch of the main functioning of any individual in terms of *body functions and structures, activities and participation, and environmental factors*. On the other hand, the WHO DAS II is an assessment instrument that gives a total score of disability based on the activities and participation domains of the ICF. Both instruments were explicitly designed to be generic assessment tools usable in a wide range of applications aiming for data comparability across conditions and interventions. This feature constitutes the primary strength and virtue of these two instruments.

However, the generic character of the ICF Checklist and the WHO DAS II may be a drawback in specialty settings. For example, a clinician dealing with patients with arthritis will need a wider range of categories to identify functions in the neuromusculoskeletal and movement-related area. A speech and language therapist, on the other hand, will require detailed description of voice and speech functions and related structures. This is the dilemma: on the one hand we need a “common base” to compare with other health conditions and interventions; on the other hand we need “variability” to capture the detail to describe the profile of a unique group. For such specialized clinical settings, “one (generic) size does not fit all” and the “devil is in the detail”.

This obvious clinical requirement has been the primary motivation for WHO in collaboration with the Department of Physical Medicine and Rehabilitation and the newly established ICF Research Branch of the WHO FIC CC (DIMDI), IMBK at the Ludwig Maximilian University Munich to develop ICF Core Sets (4). The ICF Core Sets have “common” categories that will help to address the comparability issue. These common categories are comparable to the generic ICF Checklist. The ICF Core Sets have “additional items” that give a more detailed picture for 12 chosen clinical conditions. The papers presented in this volume describe in detail the rigorous scientific process by which these 12 condition specific ICF Core Sets have been developed. Interestingly, the papers show not only the

differences but also a considerable degree of commonalities between the existing condition specific ICF Core Sets. For example, ICF categories such as *energy and drive functions* (b126), *sleep functions* (b134), *emotional functions* (b152), *pain* (b280), *muscle power functions* (b730), *walking* (d450), *doing housework* (d640), *remunerative employment* (d850) are listed at least in 10 out of 12 condition specific ICF Core Sets. Environmental factors such as *immediate family* (e310), *attitudes of health professionals* (e450), and *health services, systems and policies* (e580) are included in all 12 condition specific ICF Core Sets.

Though this is clearly work in progress, the results illustrate some valuable lessons. Firstly, clinicians easily recognize the need for examining functioning and appreciate its value in evaluating the full clinical picture. Secondly, certain aspects of functioning clearly have primacy in our understanding of what people need to do to lead a productive and meaningful life. Such primary domains appear as recurrent selections across disorders. Thirdly, clinicians also recognize the special nature of their clientele and identify particular domains unique to the specific diseases.

The ICF Core Sets approach could also be expanded to other clinical conditions (e.g. HIV/AIDS, malaria, tuberculosis, and others) to capture the impact of different health conditions. We hope that the ICF Core Sets will ultimately result in an operationalization of the ICF that provides a practical system usable by all clinicians and form a robust and sound part of clinical records.

## REFERENCES

1. International Classification of Functioning, Disability and Health (ICF). Geneva: World Health Organization; 2001.
2. Üstün B, Chatterji S, Rehm J, Kennedy C, Prieto L, Epping-Jordan J, et al. World Health Organization Disability Assessment Schedule II (WHO DAS II): development, psychometric testing and applications. (in press).
3. The ICF Checklist: Development and Application.. Geneva: World Health Organization; 2002 (document WHO/HFS/CAS/C/02.95).
4. Cieza A, Ewert T, Üstün B, Chatterji S, Kostanjsek N, Stucki G. ICF Core Set development for patients with chronic conditions. *J Rehabil Med* 2004; 36: Suppl. 44: 9–11.